

## DOCTOR OF PHILOSOPHY

### **An exploration of the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana**

Nyante, Gifty Gyamah

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# **An exploration of the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana**

**By**

**Gifty Gyamah Nyante**

**PhD**

**September 2016**



# **An exploration of the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana**

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**Gifty Gyamah Nyante**

**September 2016**

***A thesis submitted in partial fulfilment of the University's  
requirements for the Degree of Doctor of Philosophy***

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## **Dedication**

This dissertation is dedicated to my husband Felix, and four daughters, Millicent, Emmanuella, Doris and Ruth.

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## **Abstract**

### **Background**

Cerebral palsy has been identified as the most common, chronic childhood disability that causes appreciable motor deficit. Building the capacity of caregivers and improving children's functional capacities through rehabilitation programs could reduce the physical and psychological burden imposed by the caregiving process. There is paucity of information about the experiences of caregivers of children with cerebral palsy in Ghana especially those who are not receiving any form of care. The purpose of this study was to explore the experiences and perception of caregivers living in rural communities.

### **Methodology**

A descriptive phenomenological approach as proposed by Husserl was used to explore the experiences of 12 caregivers of children with cerebral palsy aged between 2 years 9 months to 14 years. The caregivers' interviews were analysed using Colaizzi's phenomenological method of data analysis framework.

### **Findings**

Two main themes emerged from the narratives of the caregivers. The first theme 'Developing personal beliefs to support the caregiving role' revealed that caregivers developed religious and spiritual beliefs to interpret their children's condition, perceive the standard of care and negatively their beliefs caused feeling of despair and sorrow. The second main theme 'Demands that shaped the experience of caring' revealed the demands included physical, financial and social demands. The essential structure of the phenomenon

demonstrated the complex interaction of personal and environmental factors in harmony with the actual demands to influence the experiences of caregivers positively or negatively. Positively caregivers achieve coping, committed to caring, hope for the future and acceptance of the condition of their children. However negatively caregivers described the triggering factors of feeling of despair and sorrow as frustration, lack of understanding of the condition, felt stigmatised and perceived that the child was going through pain and suffering.

## **Conclusion**

Caregivers derived strength from their religious and spiritual beliefs to balance the demands of caregiving. The new findings could be used as a basis for developing interventions to support caregivers, inform new strategies for rehabilitation care delivery and sensitisation of community members about inclusion of children with disabilities in the future

## **Chapter 1**

### **Background to the study**

#### **1.1 Introduction**

This thesis is committed to presenting an in-depth understanding of the phenomenon of the experience of caring for a child with cerebral palsy in the context of a rural community in a developing country. The study adopted a descriptive phenomenological approach as a means to understand the experiences of caregivers. The evidence built throughout this study informs an essential structure which offers a better understanding of the phenomenon being studied. This chapter provides the background for the study, the research aims and objectives as well as the definition of terms used in the study. It also discusses the concept of caring, the prevalence, impact, and management of cerebral palsy. The chapter concludes with a synopsis of each chapter in the thesis.

#### **1.2 Background**

My motivation for this research is to gain an in-depth understanding of the meaning caregivers attribute to their experiences of providing care for children with cerebral palsy in a rural community in order to assist health professionals to develop context tailored interventions for children with cerebral palsy in rural Ghana. I am a physiotherapist working both in academia and clinical practice with caregivers of children with different disabling conditions, whose quality of life is affected by a range of personal and environmental factors that are associated with the caregiving process. My experiences have been developed around working in tertiary institutions. Hence my knowledge before the commencement of this study concerning the personal and environmental factors that

strongly impact the lives of caregivers of children with cerebral palsy was limited to urban context. Unfortunately there is paucity of general information about all issues concerning cerebral palsy in Ghana as a whole and none from the rural communities.

Cerebral palsy has been identified as the most common, chronic childhood disability (Rosenbaum, 2003) by a majority of health and social services (Morris, 2007). During my clinical practice, cerebral palsy has been the most common childhood disability reported at the physiotherapy paediatric units. The caregivers of children with cerebral palsy receiving physiotherapy care consistently express the importance of physiotherapy services in reducing the physical and psychological burden imposed by the caregiving process. This led me to question how caregivers of children with cerebral palsy experience the caregiving process when they are unable to access rehabilitation care. A more detailed discussion of my professional and personal understanding of the phenomenon and how these influenced this study and how I addressed reflexivity is provided in the Methodology chapter (section 3.6.3.1) of this dissertation.

Although there is no available data to inform the prevalence of cerebral palsy in Ghana, the prevalence at the rural communities is expected to be high because of the poor usage of health professionals for delivery despite the availability of free obstetric care (Mills et al., 2008). A survey conducted by Mills et al., (2008) in the poorest regions in Ghana, revealed that after interviewing 3,433 women, 98% received antenatal care but only 38% delivered with the assistance of health professional. The women preferred delivering at the houses of traditional birth attendants, who were mostly old women in the community. These women have no skill training and had assumed this culturally accepted responsibility. Hence the babies delivered at the rural communities were at risk of

developing cerebral palsy. The most common aetiologies of cerebral palsy recorded in studies conducted in Africa are birth asphyxia, kernicterus and neonatal infection which are all acquired during the perinatal period (Donald et al., 2015; El-Tallawy et al., 2011; Ogunlesi et al., 2008).

My interest in the phenomenon developed further after conducting a situational analysis of the health services available to children with cerebral palsy in the poorest district in the Greater Accra Region, Ghana (Nyante, Baltussen and Asante, 2012). This unpublished study revealed that cerebral palsy was the most common childhood disability in the district but these children were not receiving any form of rehabilitation services and they were hidden in the community. Hence it was not feasible to estimate the population of children with cerebral palsy and phenomenology would be an appropriate methodological approach to use to explore the experiences of the caregivers. Phenomenological study would enable a greater understanding of the challenges that caregivers face and the findings would enhance development of future rehabilitation services. Detailed description of the rationale for choosing descriptive phenomenology was described in the methodology chapter (section 3.3).

Although the caregiving process as experienced by rural families will be similar in many ways to those of urban families, they do face a number of unique problems. An in-depth understanding of the phenomenon being studied is not possible without a thorough appreciation of the circumstances of the rural context. It is also stated that the living conditions in most rural communities are extremely poor. A report from the Ghana Poverty Mapping survey conducted in May 2015 showed that the highest incidence of poverty (55.1%) in the Greater Accra Region was from Shida Osudoku district where this study was

conducted (Ghana Statistical Service, 2015). The 2010 population and housing census of Ghana indicated that a higher proportion of males than females of the population (42.2% and 38.3 % respectively) are children younger than 15 years. The life expectancy of females and males in the country is 64 and 61 years respectively as reported by the World Health Organisation (2014).

Health service delivery in Ghana is organised in three levels, primary, secondary and tertiary. The tertiary systems include the Teaching Hospitals and Regional Hospitals where as the secondary systems include districts hospitals and Polyclinics. Primary health care is delivered through a close-to-client approach adopted through Community Health Planning and Services (CHPS) in the year 1999 (Nyonator et al., 2005). Nyonator et al., (2005) also indicated that the introduction of the CHPS initiative had improved the accessibility, efficiency, quality of health and family planning care of residents of rural communities. However there is no documentation of rehabilitation care to persons with disability as part of CHPS national health policy initiative. Health services in CHPS initiative approach are mainly delivered by Community Health Nurses who offer public health outreach, limited clinical services, and serve as the first point of contact and referrals (WHO, 2014). Although the Ministry of Health in Ghana has instituted well-structured primary health care systems, there are no rehabilitation services in the rural communities. Ghana is still facing the challenge of shortage of health professionals especially core rehabilitation professionals. The number of physicians and nurses per 1000 population in 2008 was 0.11 and 0.97 per cent respectively with only 135 registered physiotherapists (WCPT, 2015) and approximately 10 occupational and speech therapists. Therefore, in reality, physiotherapists are the only available core rehabilitation



professionals. Unfortunately physiotherapy facilities are located in the tertiary institutions and few secondary institutions in regional capitals. This situation means that many children with various disabilities are not identified and hence are without appropriate intervention. Individuals living with different forms of disabilities, including cerebral palsy, and their families in rural communities are left to struggle on their own. Many challenges compound caring for a child in a rural settlement and ranges from the absence of adequate health care, no access to potable water, no electricity, and no access to a good road network (Ghana Statistical Service, 2012) and these challenges significantly add to the burden of caregiving.

Moyer and colleagues (2014) identified the strong influence that social factors have on health related decision-making among families living in rural communities. The major factors identified were the social structure, social interactions and the cultural practices. These social factors significantly impact on families' health seeking behaviour and the development of the child particularly after the advent of disability. Hence the acceptability of rehabilitation services by community members, when they are available, and the compliance of families of children with cerebral palsy, will depend largely on social factors. The Public Health System in Ghana faces the challenge of correcting the widespread misinformation about health and childhood disability disseminated by some traditional healers and community spiritual leaders. A study conducted by Yeboah (2000) indicated that these opinion leaders are well accepted in the community since they provide simplified explanations of health conditions and promote medications made from familiar raw materials that are available in the community. As a result of misconception and spiritual linkages associated with childhood disability, there is a high probability that

children with various forms of disabilities are neglected or killed. There is also considerable stigma associated with disability that results in children being hidden by the caregivers and denied access to health care. Some authors (e.g. Greenfield and Suzuki, 1998 p. 1061) stress how important it is for health professionals to acknowledge the strengths and weakness of the existing cultural model before diagnosing developmental problems and prescribing child care interventions. It is, therefore, important to explore the experiences of caregivers in this particular cultural context. Understanding and learning from the experiences of Ghanaian caregivers living in rural communities will encourage and enable physiotherapists to explore new ways of reconceptualising physiotherapy practice and the services delivered to children with cerebral palsy and their families in the rural communities who have never received any form of care. The experiences of caregivers of children with disability have been investigated in many countries but not in Ghana. Majority of the studies are based on clinical issues of cerebral palsy and most of the participants were receiving some form of therapy. Furthermore, there is paucity of information about the experiences of caregivers living in rural areas globally including Ghana. This study provides a unique description of the caregiving process as experienced by caregivers living in deprived poor rural communities in a developing country.

### **1.3 Research Question and Aims**

The research question was, “How do individuals who care for children with cerebral palsy in a rural Ghanaian context, but who have not received any form of rehabilitation, experience the caregiving role”?

The main purpose of this study was to explore the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana

**The study objectives were:**

- To understand how primary caregivers of children with cerebral palsy conceptualise cerebral palsy and disability.
- To identify fundamental concerns associated with supporting children with cerebral palsy.
- To explore the experiences of primary caregivers of children with cerebral palsy.

**1.4 Definition of terms**

**1.4.1. Caring / caregiving**

Pearlin and colleagues (1990, p. 583) defined caring as “the affective component of one’s commitment to the welfare of another and caregiving is the behavioural expression of the commitment”. There are, however, a diversity of definitions of caregiving and the role of caregiver are evident in the literature. Bray et al. (2005) defined a caregiver as a person who performs tasks for another person that the recipient is unable to perform independently and should typically be able to perform given their age and developmental stage. This definition takes into consideration children who due to their age and development cannot perform activities independently. However, Savage and Bailey’s (2004, p. 103) definition addresses the ongoing and long-term characteristics of caregiving as well as the recipient having a form of chronic condition. They defined caregiver as a

relative, friend or a neighbour who provides practical day-to-day unpaid support for a person unable to complete tasks of daily living and a care recipient as a person who lives with some form of chronic condition that causes difficulties in completing tasks of daily living. What can be deduced from the definition is that the family member, friend or neighbour assumes the duty of caregiver when the recipient has a health condition or an impairment that limits the activities of daily living and might need special assistance. Goodhead and McDonald (2007, p. 4) affirm “caregiving arises out of relationship with the recipient in response to the need for support which is greater than normally expected due to impairment in functioning. In contrast, professionals provide formal care and, in this situation, the relationship between the caregiver and the care recipient is shaped by professional codes of conduct and the role of caregiver is associated with monetary reward. For the purposes of this study, a caregiver is defined as the person who has been identified as responsible for the day-to-day provision of assistance to a child with cerebral palsy to perform activities which are necessary for survival, human functioning or social participation (WHO, 2001) specifically assisting the child with mobility, positioning and transfer, as well as eating, drinking, bathing and dressing.

#### **1.4.2 Cerebral palsy**

The literature reveals that the definition of cerebral palsy has evolved and changed over the last 100 years. In 1861 William Little (cited in Steenbergen and Gordon, 2006, p. 780) defined cerebral palsy as a disorder that affects infants which is characterised by difficulty in grasping objects and crawling. In contrast, a hundred years later MacKeith, MacKenzie and Polani (1959) defined the condition as a persisting, but not unchanging,

disorder of movement and posture appearing in the early years of life due to a non-progressive disorder of the brain. The definition of cerebral palsy, proposed by Bax (1964), as a disorder of movement and posture that begins in early childhood due to a defect or lesion of the immature brain has been widely cited in the literature (678 studies). Forty years later, an international workshop on the definition and classification of cerebral palsy reached the following consensus: “ cerebral palsy is a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non- progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and or behaviour, and / or by seizure disorder” (Bax et al., 2005, p. 572). Central to the many definitions of cerebral palsy is the disturbance in movement and posture resulting from injury to the developing brain.

Successful diagnosis and intervention for cerebral palsy is based on continuous assessment of the clinical presentation, pattern of development of symptoms, family history, obstetric history and environmental factors (Kriger, 2006). Identifying a child with disability in developing countries including Ghana depends largely on caregivers’ expressing concerns to health professionals about a developmental delay or observed structural defect. There are huge problems associated with identifying and diagnosing childhood disability in developing countries (Maulik and Darmstadt, 2007). These problems are attributed to lack of effective screening (Biritwum et al, 2001), lack of competent health personnel to detect the condition and poor availability of diagnostic facilities (Donald et al., 2015; Frank-Briggs and Alikor, 2011), lack of country wide registers of specific health conditions (Parkes and Hills, 2010) and, above all, limited

availability of complete medical records. Parkes and Hills (2010) consider that the most reliable information about children and young people with cerebral palsy can be obtained from the systematically maintained registers most commonly found in developed countries.

Due to the lack of diagnostic facilities in countries such as Ghana, cerebral palsy has been described as a syndrome characterised by motor disability associated with significant prenatal, perinatal or postnatal medical history (Donald et al., 2014). The Community Health Nurses, who practiced in the district in which the study was conducted, had participated in a training program to assist them to identify children with cerebral palsy and subsequently to identify potential caregivers who met the criteria for inclusion in the study. The researcher confirmed the nurses' preliminary diagnosis of cerebral palsy through subjective and objective assessment during the recruitment phase of the study. Details of the procedure used to recruit caregivers of children with cerebral palsy are presented in section 3.4.3 of the methodology chapter.

#### **1.4.3 Rural**

In Ghana, rural communities are defined as a population size of less than 5000 persons and approximately 49% of the over 25 million population in Ghana live in rural areas (Ghana Statistical Service, 2012). Rural communities have diverse inherent characteristics that make them different from one another (Bigbee and Lind, 2007). The differences emerged from the differences in ethnicity, socio-economic status, and availability of health care delivery facilities, health-seeking behaviour and remoteness. For the purposes of this study, a rural community was defined as a community having a population size of less than 5000 with no health facility or only one Community Health Planning and Services compounds.

## **1.5 Concept of caregiving**

Child development is a dynamic process which progresses from infancy, when the child is fully dependent on the parents in all domains of function, to gradually growing towards independence through childhood, adolescence, and finally to adulthood (WHO, 2007). The caregiving process is a normal phenomenon that requires exclusive diligence and modification of responsibility over time as the child gradually attains independence. The process depends largely on societal expectations, culturally acceptable family roles and an obligation to one another within the family (Pearlin et al., 1990). Agreement, within informal caregiving, between the caregiver and the recipient is generally implicit and the quality of the relationship is informed by availability, familiarity and motivation (Goodhead and McDonald, 2007).

Cho (2007) opined that the provision of care by caregivers is informed by the type and nature of the relationship between caregiver and recipient of care. Within close relationships the caregiver accepts and understands the responsibilities inherent in the caregiving process. The type and nature of relationship established between the caregiver and the child with cerebral palsy serves as the foundation on which their mutual experiences are built. In developed countries parents, who are most commonly the primary caregivers, are sometimes able to arrange breaks in caring for their children with or without special needs by using childcare facilities ranging from special centres and preschools, family-child accommodation, and formal respite and kith and kin care facilities (Bromer and Henly, 2004). Formal caregiving services, i.e. not the child's relatives, often offer a holistic approach to early care and education (Cahan and Bromer, 2003). In most instances, non-relative formal caregivers are professionals who have specific knowledge

and understanding of the dynamics of child development. In contrast, in developing countries caring for children, with or without a disability, is a continuously evolving situation that involves immediate family members and other close relatives and very rarely formal caregivers. Caregivers who are relatives of the child, such as grandparents, aunts, siblings, in laws, and family friends are unlikely to have any experience or skill in caring for a child with disability and, as a result, the caregiving role and responsibilities has a major impact on the quality of life of the caregiver.

In the developing countries where the extended family system is the normal practice, caregivers are often grand- parents or any significant individual who does not have the capacity to work and earn to support the family. There is an ideology that once an adult is ‘house bound’ then his or her presence in the home should be all that is required to care for the children. In some instances the only thing the caregiver can do for the child is ensure their safety and make sure that they are protected from injury. Caregiving in this context is considered synonymous with employment and the assumption is made that the stressors experienced are outweighed by the personal benefits that the caregiver experiences. During the process of caregiving, depending on the relationship with the child, the caregiver designs strategies to teach the child and promote cultural values in an attempt to prepare the child for adulthood. However, caregiving becomes extremely stressful when the child has special needs that need to be met. In a rural setting, although caregivers may have knowledge of the family and child’s needs and are motivated by family bonds and culture, they also may lack the expertise to care for the child especially when they need special care and this can cause different forms of stress.



A number of authors (Huang, Kellett , Kellett and St John's, 2011; Raina et al., 2005) have suggested that caregivers of children with cerebral palsy experience severe stress related to caring for their children. Pearlin and colleagues' (1990) proposed a stress process model that identifies four main domains: background and the context of stress, the stressors, the mediators of stress, and the manifestation of stress. The model identifies the background and the context of stress as including demographic and recognised characteristics of the caregiver, the relationship between the caregiver and care recipient, and the social and service delivery environment, which inform the context in which, the care is provided. In the second domain, the model identifies two main categories of caregiver stress: primary (characteristics of the care recipient that explain the task and the responsibilities assumed by the caregiver) and secondary (caregiver's life which includes family, occupation and social roles). The third domain, describes the mediators of stress as conditions, principally coping mechanisms and societal support, that cause the variability in individual experiences and responses to similar stressful situations. Lastly, the manifestation of the stress denotes the outcome of the stress process, that is, the impact of the stressful condition on the individual's mental and physical well-being and ability to sustain societal roles.

Haley and Harrigan (2004) proposed that every individual has a unique perception of stressors and their strengths in managing stress and these are influenced by the person's unique culture or worldview. The principle informing this model of the stress process is that the perceived strengths and stressors of every individual are connected by dynamic energy flow and influenced by the person's current experience and sense of harmony (Haley and Harrigan, 2004). According to Haley (2009) the harmonic state is individual

and each person achieves core equilibrium when there is a free flow of energy between perceived strengths and stressors. Ratliffe and Haley (2002) view harmony as the lens through which each person views the world and this unique perspective influences whether they will emerge into a position of empowerment (energy/ connectedness) or victimization (judgement / dualism).

In exploring the perception of caregivers' experiences, both the strengths and stressors need to be addressed to give a comprehensive picture of the harmony or equilibrium that has been achieved. It is also assumed that there will be considerable diversity, among caregivers who share a similar culture as well as from different cultures, in the manner in which they embrace and experience the caregiving role and the actual caregiving tasks. According to Sam (2001) the act of caregiving is influenced by the value the family place on the child and parental belief system. In Ghana, especially among those living in the rural areas, children are important for the economic productivity of the family. Children are expected to be actively involved in household chores such as cleaning, going out to fetch water, taking care of their younger siblings, petty trading and helping in the farms, as well as eventually doing all the errands in the house. In view of the recent economic hardship in Ghana, the child labour phenomenon is increasing. Although there is paucity of information regarding the economic cost to the family of caring for a child with disability in Ghana, children with disability will presumably be more expensive than productive. How this will affect the act of caregiving in a society where high economic value is placed on children is a question that needs more investigation.

Furthermore, the extended family system is often used to provide financial support to disadvantaged and poor members of the family. However, in recent times Ghana has

experienced higher cost of living, higher unemployment rates and a consistent decline in economic growth. All these challenges influence the role of the extended family system and have implications on the act of caregiving especially when the child is disabled and requires extra attention, financial expenditure, and specialised care. As a result, children with severe disability may be perceived as a great misfortune by the parents and this perception may affect the quality of caregiving, the value placed on the child, and the psychological stress associated with caregiving.

## **1.6 Summary of Thesis**

Chapter one introduces the thesis by highlighting the significant issues related to the background of the study. It also presents the socio-economic context of the caregivers participated in the study and announced the research questions, aims and objectives. Chapter 2 reviews the different school of thoughts available in literature concerning caregiving for children with cerebral palsy. The chapter again explores the methodological approaches mostly used by authors and the different themes emerged from different culture context. The chapter concludes with a summary of the position of this study in literature and the contribution that it offers to knowledge. A section on the overview of the prevalence, clinical presentation and management of cerebral palsy is included in the chapter

Chapter 3 describes in details the methodological process of the study. A keen interest was geared towards the choice of methodology, the philosophical and paradigmatic assumptions taken to arrive at the choice of using descriptive phenomenological approach. It also describes the research design of the study. The process of being transparent to

improve the rigour of the study is demonstrated in the chapter where every details of the research process were documented. Chapter 4 presents the finding of this study, and chapter 5 portrays the essential structure of the phenomenon. Chapter 6 covers the discussion of the findings and it also places interest in the critical review of the essential structure in relation to International Classification of Function and Disability ( ICF ) concept, social model of disability and integrated model of harmony. The final chapter 7 presents the conclusion of the study. The chapter describes how the objectives of the study were met and the implication of the findings to physiotherapy and rehabilitation practice and education.

## **Chapter 2**

### **Literature Review**

#### **2.1 Introduction to the chapter**

The phenomenon being studied is the experiences of caregivers of children with cerebral palsy who had never received any form of rehabilitation. The previous chapter introduced the thesis and highlighted the background and context of the study as well as the definition and aetiology of cerebral palsy. A discussion of the concept of caregiving was also included in chapter one. Hence this chapter develops the discussion by providing a review of the current research literature related to the phenomenon of caregiving. The last section of this chapter presents a review on the prevalence, clinical presentation and management of cerebral palsy.

A systematic search was conducted to identify studies that focused on the experiences of informal caregivers. Integrative (determining the current state of knowledge) and thematic types of review were adopted for this literature review (Cooper, 1989 cited in Moustakas, 1994: p.112). The process of an integrative review involves a review of literature relevant to the topic, which consist of defining the problem, outlining the data collection procedure, evaluating the data, and then drawing a conclusion by analysing and interpreting the findings. On the other hand a thematic review entails organising the core themes identified in the studies being reviewed and presenting them as one core descriptive theme. Russell (2005) highlighted the benefits of an integrative literature review as identifying the gaps in the current research, identifying central issues in an area and exploring which research methods have been used successfully. Likewise

thematic review offers a summary of the chosen body of literature, new perspectives and understanding of a phenomenon (Ferragina and Seeleib-Kaiser, 2011). Hence the use of these review types will facilitate the flexibility required to include different research design approaches that inform the phenomenon of caregiving as well as justify my choice of qualitative research and identify the gap in the research that my study will potentially address. For the purposes of this study the review was conducted in three phases. An overview of the review structure - what was done in each phase and the timescale – is provided in Table 1.

**Table 2.1. Literature review structure**

Phases	One	Two	Three
Period	2013	Early 2015	Late 2015
Type of review	Integrative	Integrative	Thematic
Activity	Define the problem and outline the methods of data collection, draw conclusions about the knowledge the studies sought to obtain and the gap that needs addressing.	Evaluate the data obtained from the study, analysis and interpretation of the findings,	Organise core themes presented in the reviewed studies, then demonstrate a better understanding of the themes.

These three phases were conducted at different stages; during the proposal stage, after data analysis and during the final write up respectively. The timing of these phases was chosen to conform to the philosophical stance of descriptive phenomenology. Some researchers support and advocate that the descriptive phenomenologist should not conduct a detailed review before conducting the study (Speziale, Streubert and Carpenter, 2011; Lopez and Willis, 2004). According to Speziale, Streubert and Carpenter (2011: p. 25), the

main reason is to reduce the likelihood of the researcher developing suppositions or biases about the topic being studied, so that the researcher will be in the position to authentically present the phenomenon as experienced by the participants. For ease of reading and to avoid repetition, the findings of the three phases of the literature review are combined in this chapter. This chapter concludes with a summary of the review.

### **2.1.2 Procedure**

With the background and context of the phenomenon being studied, the main focus of my literature search was on qualitative studies. Qualitative studies would provide a better understanding of the phenomenon and it would not restrict the participants to pre-established questions, but rather it would give the participants in the various studies the opportunity to give an accurate reflections of their perceptions and understanding of the phenomenon being studied. Hence, I assumed that the knowledge produced by qualitative studies would capture the complex context of the study topic. A qualitative systematic review was employed. According to Grant and Booth (2009) “ the method used in qualitative systematic review is integrating findings from qualitative studies and it looks for themes or constructs that lie in or across individual qualitative studies” (p. 94). Locate Coventry University Subject Resources online access was the main website used for the entire literature search. The subject area chosen was Health. The health website comprised of 25 different databases. After reading through the description of the databases, five databases were chosen as the most likely to reveal published research about the experiences of caregivers of children with cerebral palsy. Qualitative systematic review method allows the flexibility to employ selective or purposive sampling of databases

(Grant and Booth 2009, p. 94). The main databases searched included the Academic Search Complete, AMED, CINAHL, MEDLINE, PsycINFO and Scopus. The first step was a search of the CINAHL headings because it permits searching major concepts and additional terms within their term list. Cerebral palsy and caregiving (caregivers list; parents or sibling or mother or father or women or men) were combined in a single search and revealed 48,485 hits. By restricting the list to life experience, psychological, psychosocial impact and cerebral palsy the number of hits were reduced to 4,771. Focusing on studies with cerebral palsy as the subject the number was reduced to 227. Limiting the search to a specific time frame (2005 -2015) and to English language and academic peer reviewed journals resulted in 217 articles. In the second search, Academic Search Complete, AMED, CINAHL, MEDLINE, PsycINFO were all selected using EBSCO host. A search using the keywords cerebral palsy and caregiver revealed 594 hits, and by adding the keyword 'experience' this was reduced to 92 hits. Combining cerebral palsy, mother and experience revealed 107 hits, cerebral palsy and father and experience 22 hits, and cerebral palsy, sibling and experience 14 hits. Finally the same search was conducted in Scopus, which resulted in 73 articles. Therefore a total of 304 articles were identified through database searching. After each search, the article abstracts were read and articles that met the inclusion criteria were selected into a folder. Exact duplicates were removed from the folder.

The selection of the studies was informed by the following inclusion criteria; primary research relating to cerebral palsy, study should have a well-defined research approach and study design that appeared to inform the research topic; the study setting



should define geographical context which depicts cultural and socio-economic characteristics, and detailed description of the participants being studied; the relationship of the participants to the child with cerebral palsy should also be stated. Studies focusing exclusively on the experiences of caregivers with respect to the child with cerebral palsy going through particular interventions like surgery, home exercise or forms of therapy were excluded because the focus would not reflect the holistic nature of 'caring'. The initial impression was that majority of the studies were conducted in developed countries and clearly not much research has been conducted related to cerebral palsy in Ghana. A search with no date restriction for studies conducted in Ghana on cerebral palsy revealed only three studies, a survey study on the psychological impact of cerebral palsy on families (Olawale, Deih and Yaadah, 2013), a case report focused on complications associated with cerebral palsy (Arthur, 1995) and an epidemiological study linking mercury poisoning with the prevalence of cerebral palsy (Elhassani, 1982). These studies did not meet the inclusion criteria for this review and were excluded. A total of 16 articles were selected for the review and included 13 qualitative and 3 mixed methods (combining qualitative and survey approaches), studies.

The role of caregivers of children with cerebral palsy exceeds the normal activities of parental care in terms of the temporal nature of the role, its intensity and complexity (Burkhard, 2013). In the early stages of a child's development (post birth and babyhood), caregivers' experiences are not that different from 'normal' babies due the common dependency of the child and lack of expectations of independence at these stages. Caregivers of children with cerebral palsy begin to create different meanings for their

experiences after learning of the child's condition or when they recognise deviation from normal child development, otherwise the stresses and strains they experience are deemed part of the expectation of normal parenting. According to Uldall (2012), caregiver burden can be objectively assessed mainly in relation to the socio-structural constraints they experience, which include inequalities in health care delivery, lack of family resources, limited access to social networks and support, and subjectively by assessing the psychological stress experienced by caregivers. Given the aim of the study to investigate the experiences of caregiving from the individual perspective this review focused on two main dimensions. First, the indirect impact of cultural and socio-economic factors on the primary caregiver and, second, the direct impact of the impairments associated with the cerebral palsy. The review is therefore organized using the following headings: Cultural and socio-economic impact on the caregiving process and the impact on the caregiver of caring for a child with cerebral palsy.

## 2.2 Cultural and socio-economic impact on the caregiving process

Cultural beliefs and socio-economic factors provide an important context and background information to the act of caring. A detailed review of eight qualitative studies emphasising the influence of socio-cultural context on the experiences of caring for a child with cerebral palsy are discussed. References presented in the table below.

**Table 2.3 References of studies stating cultural and sociodemographic issue**

No.	Reference	Country of origin
1	Gona, J. K., Xiong, T., Muhit, M. A., Newton, C. R., and Hartley, S. (2010) 'Identification of People with Disabilities using Participatory Rural Appraisal and Key Informants: A Pragmatic Approach with Action Potential Promoting Validity and Low Cost'. <i>Disability &amp; Rehabilitation</i> 32 (1), 79-85	Kenya
2	Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., and Chavuta, A. (2005) 'How do Carers of Disabled Children Cope? the Ugandan Perspective'. <i>Child: Care, Health and Development</i> 31 (2), 167-180	Uganda
3	Huang, Y., Kellett, U. M., and St John, W. (2010) 'Cerebral Palsy: Experiences of Mothers After Learning their child's Diagnosis'. <i>Journal of Advanced Nursing</i> 66 (6), 1213-1221	China
4	Huang, Y. P., Kellett, U., and St John, W. (2011) 'Being Concerned: Caregiving for Taiwanese Mothers of a Child with Cerebral Palsy'. <i>Journal of Clinical Nursing</i> 21 (1-2), 189-197	China
5	Kuo, Y. and Lach, L. M. (2012) 'Life Decisions of Taiwanese Women Who Care for a Sibling with Cerebral Palsy'. <i>Health Care for Women International</i> 33 (7), 646-665	China
6	McNally, A. and Mannan, H. (2013) 'Perceptions of Caring for Children with Disabilities: Experiences from Moshi, Tanzania'. <i>African Journal of Disability</i> 2 (1), 1-10	Tanzania
7	Milbrath, V. M., Cecagno, D., Soares, D. C., Amestoy, S. C., and Siqueira, Hedi Crecencia Heckler de (2008) 'Being a Woman, Mother to a Child with Cerebral Palsy'. <i>Acta Paulista De Enfermagem</i> 21 (3), 427-431	Brazil
8	Scheidegger, G., Lovelock, L., and Kinébanian, A. (2010) 'The Daily Lives and Occupations of Tibetan Families Who have a Child with Disabilities'. <i>Scandinavian Journal of Occupational Therapy</i> 17 (4), 286-298	China

These studies were selected based on the authors stating their interest in cultural and socio economic issues as part of the research problem. These studies suggest that each culture has its own fundamental structure and on-going responsibilities required of each

generation. The studies reviewed addressed the influence of culture, beliefs and socio-economic factors on parents' reactions to learning the diagnosis of cerebral palsy and being a parent of a child with cerebral palsy (Huang, Kellett and St John, 2010); how they accepted the role of caregiving (Kuo and Lach, 2012; Scheidegger, Lovelock and Kinèbanian., 2010), challenges and coping associated with the role (Huang, Kellett and St John, 2011, Hartley et al., 2005) and how they adapted to having a child with cerebral palsy (Milbrath et al., 2008).

### **2.2.1 Cultural and traditional beliefs impact on how the diagnosis of cerebral palsy is interpreted**

The initial plight of mothers begins when their child's diagnosis is disclosed and conveyed to them (Uldall, 2012). The studies reviewed suggest that the diagnosis of cerebral palsy was interpreted through the lens of the individual's cultural beliefs and context and these determined the level of stress experienced (Huang, Kellett and St John, 2010). According to Helman (2007, p.2) culture is "a set of guidelines that individuals inherit as members of a particular society, and that tell them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people or supernatural forces". Cultural continuity becomes a tradition. Huang, Kellett and St John (2010) used a hermeneutic phenomenological approach, which is presumed to be more interpretive than pure descriptive, to demonstrate that the cultural context was integrated with the meaning parents attributed to learning that their child had cerebral palsy and influenced the process of caring. The meaning, as revealed in the findings, included feeling out of control and disempowered because the information destroyed their hope of having a

healthy child; mistrusting health care professionals as being careless and lacking in the competence necessary to ensure that the child would receive optimal medical assessment and diagnosis; feeling a sense of release after learning the diagnosis as a confirmation of long held suspicions about their child's developmental delay and finally, feeling blamed for not following traditional cultural practices and breaking traditional Chinese taboos particularly during pregnancy. The study clearly revealed that a "mother of a child with disability can be blamed for the child's condition resulting in dysfunctional family relations and poor support" (p. 1219). The authors identified two underlying aspects of the cultural context that influenced these perceptions: (1) the traditional belief that a child's parents, family members or ancestors may have done some misdeeds to merit the child's condition, and (2) social stigma, discrimination and rejection of persons with disability within the society. These environmental factors would perpetually influence the caregiving process, hence the caregiver is required to adapt and cope. According to Milbrath et al. (2008) each individual, when constantly exposed to internal and external stimuli, goes through an adaptation process in a specific and unique way. Using a descriptive exploratory methodology, Milbrath and colleagues "explored the process of adaptation experienced by a woman, motivated by the birth of a child with cerebral (p. 428). Women participants (n=6) in Milbrath and colleagues' study (2008) faced challenges in the process of adapting to the birth of a baby with cerebral palsy due to the societal defined standard of a 'successful' woman as being a woman who delivered a healthy baby. As a result, the participants' feelings, as women, of competence and power related to procreation were shattered. Furthermore the women abandoned their personal, professional and social lives to take care of their children with special needs.

Similarly, the conceptualization of disability in some African communities has negative implications for caregivers. Gona et al. (2010) used a phenomenological approach to explore the lived experiences of caregivers of children with disability in a poor rural community in Kenya. The authors focused on the challenges and coping strategies of the participants and revealed that the birth of a disabled child affected the expectations of caregivers and they experienced emotional pain and feelings of devastation after the disclosure of the child's disability. These experiences were influenced by the cultural perception that the future prosperity and well-being of families depended on their children. Apart from the shattered future dreams, participants expressed the following challenges related to cultural beliefs: stress in the form of insufficient time for other chores and rumour-mongering about them and the baby because of the cultural beliefs and superstitions related to disability and the complex associations made between disability and being possessed by evil spirits, punishment from God or witch craft. A phenomenological study conducted in Uganda discussed similar beliefs among the participants (Hartley et al., 2005). Hartley and colleagues explored how families with children with disability living in rural areas cope when there are no services for their children and the problems they face as well as the strategies they used to overcome the problems. Participants in the study expressed that they felt compelled to use large sums of money to constantly look for a cure for their child's impairment from both formal medical personnel and traditional healers given that previous treatments had not been successful. It was also reported that participants received both social and physical support from family and disability organisations, but despite this participants also expressed that they faced

negative attitudes from others that included, rejection and abuse leading to feelings of loneliness and isolation.

### **2.2.2 Impact of culture and traditional beliefs on the role of caregiving**

Two phenomenological studies, Kuo and Lach, (2012) and Hartley et al. (2005), conducted in Africa and Taiwan respectively, clearly showed that the role of daily caregiving of children with cerebral palsy or any form of disability was assigned primarily to female carers, particularly mothers and grandmothers. Although, the majority of the participants in the studies reviewed were women, little detailed discussion of the culturally prescribed role of women was provided. In my experience the roles of women are very different from men in many cultural contexts and have not been consistently addressed in the research literature. A number of authors (Huang, Kellett and St John, 2010; Huang, Kellett and St John, 2011; Kuo and Lach, 2012) discussed aspects of the Chinese culture and its impact on the caregiving role. These studies provided a vivid description of the Chinese culture, which is deeply influenced by Confucianism and is mainly concerned with respect of each individual role in a relationship. They coined the idea that: “Men manage external affairs and women manage internal affairs”, implying that boy or girl children are expected to carry on these socially required roles (Kuo and Lach, 2012, p. 650). According to Kuo and Lach (2012) western feminist theory and Confucius theory in Taiwanese society inform an understanding of women’s role as caregivers. Both theories argue that the traditional societal roles of men and women are different so both sexes are taught to be different from the moment they are born. The gender based division of labour

defined caregiving as a feminine role. Making reference to Gilligan (1982) feminist moral theory, one of the moral developments of a woman is “adoption of societal values and define her self-worth on the basis of her ability to care for and protect others” (p. 649). Kuo and Lach further states that women’s role is developed consciously or unconsciously from the early relationship they established with their mother. As the mother cares for her daughter, the daughter then develops the female identity and responsibility. Confucius theory summarise women’s and men’s roles as internal and external affairs. Women are mostly responsible for internal affairs like cooking, caring for children, and doing other household work, whereas men go outside to work for the financial upkeep of the home. Hartley et al. (2005) describes the man’s role as gatekeeping because their responsibility is mainly provision of money and material resources.

Kuo and Lach (2012) explored how the participants’ experiences in the Taiwanese context shaped their life decisions and their data revealed how the caregiving experiences were influenced by the moral philosophy that, in general, guides the culture and behaviour of people in Taiwanese society. The methodology used was a phenomenological approach and it was described in depth. The participants were sisters of a child with cerebral palsy and recruited through purposive sampling and snowball techniques. Each participant was interviewed twice but the time interval between interviews was not recorded. The authors stated they used a modified Stevick-Colaizzi –Keen method for their data analysis. Three main themes emerged, two describe an aspect of caring (caring through interpretation and caring through protection) and the third describes an act of caring (caring through sacrifice). The findings describe how the participants experienced tension, as they were



required to negotiate between the caregiving role and the socially expected role in making life decisions. Caring through interpretation was how the participants attributed meaning to their ability to understand the feelings and intentions of the children with cerebral palsy particularly those with speech impairments. They considered that their feminine role of long-term interaction with their disabled sibling contributed to their ability to understand them and they had contrary opinions about the ability of their male counterparts to develop this degree of understanding. Likewise their long-term interactions with their sibling caused them to witness incidents of teasing and bullying of their brothers or sisters with cerebral palsy and this increased their determination to protect them. The participants' conceptualized caring in terms of sacrifice and care for their sibling although for some this caused difficulty and conflict. As females they had no family property rights, and if married, they were expected to spend their energy and time on supporting the husband's family members rather than own. The unmarried participants suggested that their choice of husband was sacrificed as they were seeking men who would be willing to compromise the Taiwanese cultural beliefs and support their commitment to caring for their sibling with cerebral palsy.

Scheidegger, Lovelock and Kinèbanian (2010) used an ethnographic approach to explore the experiences of Tibetan families of children with disability living in a remote village in order to understand their experiences and cultural context. The researchers spent extensive time with two families and collected data for eight weeks. On each visit the research team of four people recorded their field notes and observations, and wrote the conversations they had independently with family members. The data were compiled and

compared at the end of eight weeks. Scheidegger, Lovelock and Kinèbanian (2010) found that the participants were immersed in a culture very different from the Western context but, despite this, the parents had similar hopes and understanding about how to care for their children. The researchers also highlighted that the families' perceptions about the cause of disability and treatment were influenced by their religious beliefs and culture. The families expressed their loss of hope for the future of their child with cerebral palsy, and described how one person gave up employment in order to care for the child with financial implications for the whole family and there were costs associated with seeking a cure. The researchers recommended that local health workers should be fully involved in rehabilitation interventions to build trust and study the impact of the local culture and behaviour on care for children with disability and that therapy treatment schedules should be flexible to allow families to participate in cultural festivals which were a major priority for them.

### **2.2.3 Impact of socioeconomic factors on caregiving**

Socioeconomic factors were shown, in a number of studies, to have both negative and positive impacts on the role of caregiver, for example, negative attitudes of the family members and the society at large were clearly identified (Hartley et al., 2005; Huang, Kellett and St John, 2011). Huang, Kellett and St John (2011) used a hermeneutic phenomenological approach to explore the challenging experiences of 15 mothers who were primary caregivers of children with cerebral palsy in a Chinese social context. The findings demonstrated that the challenging relationships established between the mother of a child with cerebral palsy and the family, as well as the larger Chinese society, influenced

the support that the mother received in caring for their child. The high levels of psychological stress experienced by caregivers of children with cerebral palsy are related to lack of family acceptance and support, and the degree of stigmatization they experienced. The mothers reported that they experienced feeling burdened as the sole primary caregiver, being marginalized by others especially their in-laws and husbands and that they had limited or no professional support. The mothers who participated in the study expressed feelings of anger and confusion when they received inconsistent information about their children. In Huang, Kellett and St John's (2010) previous study mothers of children with cerebral palsy experienced "shame, a sense of inferiority, self-debasement and social rejection" (p. 1214) for delivering, and caring for, a child with cerebral palsy in the Taiwanese culture. They found that family members were reluctant to accept the child with cerebral palsy or viewed the child as a liability and found these attitudes very challenging. Huang, Kellett and St John's (2011) study highlights the importance attributed to the family and the important contribution of the individual caregiver to the traditional Chinese family. Similarly, the studies conducted in Africa identified that the main problems encountered by caregivers' of children with disability including cerebral palsy related to the negative attitudes of the society. Participants' experienced rejection by family members and peers because of the belief that children with disabilities are shameful and embarrassing to the family and should be hidden (Hartley et al., 2005) and isolated from community activities (Gona et al., 2010). In particular, McNally and Mannan's (2013) phenomenological study conducted in Tanzania, with the purpose of gaining insight into how having a child with disability impacts on participants lives gave a comprehensive description of the experiences in an African context (p. 1). The

study revealed that participants had experienced overt stigma and discrimination in the form of gestures, such as, pointing, laughing, and staring and rejection by family members, and nearly half of the participants mentioned that their husbands left them once they knew their child was disabled. In contrast, five of the six participants in the study conducted by Milbrath et al. (2008) described their husbands and family members as their main support network that helped them to adapt to their caregiving role. It was clear from these studies that positive social support, such as financial, emotional and affective help in caring for the child with disability is essential in reducing the stresses associated with caregiving. According to some authors, any family that accepts the birth of a child with cerebral palsy goes through structural reorganisation and redefinition of roles and this can promote internal family unity. Social support from neighbours and from a spiritual community also promoted coping and contributed to wellbeing of the caregivers (Hartley et al., 2005; Scheidegger et al., 2010; Gona et al., 2010). Poverty and financial hardship were the main concerns in most of the studies reviewed. The theme of constantly searching for a cure, particularly evident in the studies conducted in Africa, was associated with huge expenditure on hospital bills and transportation (Hartley et al., 2005, Gona et al., 2010).

#### **2.2.4 Section Summary**

The perception of disability has negative implications for the caregiving process (Gona et al., 2010). Societies interpret the meaning of disability in many ways and these affect the attitudes of members of a particular society towards persons with disability. The literature reviewed in this section clearly showed that the cultural and social context in which participants experience caregiving and the perception of families about disability

contribute to the challenges experienced by caregivers. Caregivers of children with cerebral palsy experience unique and individual psychological stress informed by their specific beliefs and culture that also influenced the strategies they adopted to cope with their problems (Gona et al., 2010). Caregivers' perceptions and beliefs about disability are important contributing factors in their healthcare- seeking behaviour, and a number of studies have highlighted the importance of health professionals' understanding how persons with disability and their families conceptualize disability (Danseco, 1997; Maloni et al., 2010).

Groce (1999: 4) suggested that “the knowledge of traditional beliefs and practices towards disability is of vital importance in planning and implementing programmes for individuals with disability that will make a real difference in their lives in the communities in which they live.” Different cultures show a broad range of perspectives which place people with disabilities on a continuum from human to ‘sub-human’. These perceptions are informed by the social context in which care is provided and contribute to the stresses experienced by people with disabilities and their caregivers. When persons with disabilities are stigmatized and not valued by society, they may be perceived as demonic or unfortunate and often outcast by their communities. Huang, Kellett and St John (2011:189) concluded that “poor support and dynamics will emerge when family members regard disability as a loss of face and stigma.”

The studies reviewed in this section have contributed to the design of this study by raising my awareness about the impact that parental beliefs and culture have on the act of caregiving in a culturally rooted environment. Although globalization has had an impact on

the life style of Ghanaians, citizens living in the rural areas are still entrenched in the traditional Ghanaian cultural practices and values. Ghanaians are divided into ethnic groups and further into clans. Members of the same clan are believed to be bound by spiritual and other specific obligations. Individual members of a family may belong to a different clan either the mother's or father's clan or both depending on the lineage (matrilineal or patrilineal). This means that children are not regarded as belonging to their parents rather to their lineage. Individuals who have their heritage from the matrilineal line pay attention to the fertility of their female children to ensure that their society will not die but can be continued by their female child. In such a society the mother is expected to inculcate these roles and expectations in the child at a very early childhood stage. Likewise the mothers' security in old age may be indirectly linked to their male children, who will be expected to inherit the wealth of their uncles, that is their mother's brothers. Likewise the patrilineage comprises of a kin group related to a common male ancestor, and the male child is governed by the related expectations (Laird, 2011). Laird (2011) pointed out that these family systems continue to have a major influence on social relations in contemporary Ghana. Given this cultural background, a child with severe disability in Ghana will almost certainly be considered a great misfortune for and by the parents and this perception influences the nature and role of caregiving, the value assigned to the child, and the psychological stress of caregiving. These are all issues that need to be systematically explored through research.

### 2.3 How do primary caregivers of children with cerebral palsy experience the care giving process?

Four qualitative studies reviewed are discussed under the general theme, the impact of cerebral palsy on the caregiver. The impact of cerebral palsy on caregivers and the entire family is considerable and associated with their physical and psychological wellbeing. The discussion was particularly on the burdensome nature of caring, the psychological and physical health of caregivers. References, type of study and origin presented in table 2.4.

**Table 2.4 References of studies addressing impact of cerebral palsy on caregivers**

No	Reference	Type of study	Origin
1	Appelbaum, M. G. and Smolowitz, J. L. (2007) "Appreciating Life: Being the Father of a Child with Severe Cerebral Palsy" <i>Journal of Neuroscience Nursing</i> 44.1, 36-42	Phenomenology	USA
2	Burkhard, A. (2013) 'A Different Life: Caring for an Adolescent Or Young Adult with Severe Cerebral Palsy'. <i>Journal of Pediatric Nursing</i> 28 (4), 357-363	Phenomenology	USA
3	Dalvand, H., Hosseini, S. A., Rassafiani, M., Samadi, S. A., Khankeh, H. R., and Kelly, G. (2015) 'Co-Occupations: The Caregiving Challenges of Mothers of Children with Cerebral Palsy'. <i>British Journal of Occupational Therapy</i> , 5 (1), 1-10	Phenomenology	Iran
4	Geere, J., Gona, J., Omondi, F., Kifalu, M., Newton, C., and Hartley, S. (2013) 'Caring for Children with Physical Disability in Kenya: Potential Links between Caregiving and Carers' Physical Health'. <i>Child: Care, Health and Development</i> 39 (3), 381-392	Mixed Method	Kenya
5	Green, S. E. (2007) "'We're Tired, Not Sad": Benefits and Burdens of Mothering a Child with a Disability'. <i>Social Science &amp; Medicine</i> 64 (1), 150-163	Mixed Method	USA
6	Magill-Evans, J., Darrah, J., and Galambos, N. L. (2011) 'The Parenting Journey of Mothers of Young Adults with Multiple Impairments'. <i>Journal of Developmental and Physical Disabilities</i> 23 (3), 183-193	Mixed Method	Canada
7	Whittingham, K., Wee, D., Sanders, M., and Boyd, R. (2011) 'Responding to the Challenges of Parenting a Child with Cerebral Palsy: A Focus Group'. <i>Disability &amp; Rehabilitation</i> 33 (17), 1557-1567	Qualitative	Australia

### **2.3.1 The burden of caring for a child with cerebral palsy**

Higher levels of burden of care among caregivers of children with cerebral palsy than parents of normally developing children have been consistently identified in the literature. These levels of burden are primarily associated with the activities that the caregiver needs to engage in to ensure that the special needs of their children are met. Children with cerebral palsy experience various degrees of impairment in motor function which often interferes with their ability to physically independent and requires that their caregivers provide support for routine activities of daily living such as dressing, feeding, bathing and functional mobility (Novak et.al. 2009). Caregivers also take responsibility for seeking possible treatment and supporting any recommended interventions. Some authors (for example; Dalvand et al. 2015; Pierce, 2009) refer to the activities of daily living as occupations and the help given to the children by caregivers as caregivers' co-occupations. These can be simply defined as the assistance provided by a caregiver to support a child who is unable to perform desired or required occupations independently (World Health Organisation, 2007).

Dalvand et al. (2015) conducted a qualitative study involving sixteen mothers who have experienced caring for a child with cerebral palsy for five or more years. The findings revealed common aspects of the experiences of co-occupation. The four themes derived from the data were coping with self –care problems which included the child's personal care, lifting and carrying due to lack of assistive devices as well as chores outside home, such as, taking the child for treatment, to school, shopping and extra-curricular programmes. The second theme focused on the effort required to get treatment



follow-ups, which was experienced as an ongoing struggle with medical professionals and implementing treatment, and trying to practice rehabilitation exercises. The third theme related to the challenges of supporting the child's educational needs, which included accompanying the child to school and assisting with school homework. The final one identified limited parental personal leisure time because of the need to be a playmate and engage the child with cerebral palsy in everyday recreation. The child's personal care, and the need to lift and carry them gradually becomes more difficult as the child ages and the mother is also going through physiological changes associated with the aging process (Burkhard, 2013). Burkhard (2013), conducted a phenomenological study exploring the lived experiences of 11 mothers of adolescents and young adults with severe cerebral palsy who expressed that the caring role required specific competencies especially as the child got older and that the unchanging nature of the care they provided over time caused them to become exhausted. This was in contrast to their peers with non-disabled children who they saw as experiencing a sense of freedom as their child matured. The participants in Burkhard's (2013) study did report that: "their ability to lift and transfer their child was linked to self-expectations of successful caregiving" (p.359).

### **2.3.2 Physical, psychological and social health consequences of caregiving**

The demands of caring for children with disability including cerebral palsy can have a devastating effect on the general health of caregivers and they experience wide-ranging changes in their lives because the caregiving role is ongoing throughout the child's life (Raina et. al., 2005). The psychological and physical health of the caregiver is an

important component that will have direct impact on the quality of life of children with disability. Caregivers who have health problems are unable to meet the demands of caregiving and the needs of the child. An understanding of the experiences of caregivers and what they offer to the child is of much interest in developing relevant rehabilitation services. Using a mixed methods approach, Geere and colleagues (2013) explored the potential links between providing care and the physical health of caregivers in a low-income country, Kenya. A structured physiotherapy assessment was administered with each participant, which included a structured questionnaire and physical assessment involving range of movement measurement, manual muscle strength testing and palpation. This assessment revealed that all the 20 participants of the study reported having chronic pain that persisted 3 months, which they attributed to the environmental challenges associated with caring for their child over the long term, and they had passive and active movement restrictions due to pain. The qualitative aspect of the study involved one-to-one in-depth interviews in which participants reported feeling generally unwell, experiencing weight loss and medication consumption, guilt, and difficulty performing activities and work. These findings indicated that participants perceived an association between caring and the physical symptoms they were experiencing, which had an impact on essential caregiving activities. Whittingham et al. (2011) used a focus group discussion to explore the parental challenges of 8 parents of children with cerebral palsy. The findings identified that participants experienced considerable time pressures and additional parental tasks associated with caring for a child with cerebral palsy that contributed to their poor physical health. The participants described the diverse strategies they developed to manage the behaviour of their children and other parental responsibilities and the psychological stress

these caused them and, in particular, described the stress caused by the public scrutiny they experienced.

A qualitative study conducted in India (Nimbalkar et al., 2014) suggested that caregivers of children with cerebral palsy face a wide range of psychosocial problems that affect the quality of care they offer to their children. The authors used a focus group discussion method to collect data from 13 parents attending rural and urban hospitals with their children. The authors identified differences between rural and urban participants in terms of accessing information. They perceived that participants from the rural settings disclosed their views more openly when compared to those from urban settings. Common themes generated from both discussions revealed that participants experienced health problems, such as, shoulder and back pain and emotional problems from anger, fatigue and frustration that they associated with their role of caregiver. The social consequences identified were reduced participation in social gatherings, limited interactions with relatives, and lack of understanding from their community and the broader society. They attributed their social difficulties to their continuously being engaged in the care of the child. The participants also reported facing financial problems as a result of paying for consultations, medications and transportation. Although Nimbalkar and colleagues (2014) did not state any differences in experiences of caregiving between rural and urban participants, it was their opinion that participants recruited from the urban-based hospital appeared to be poorly adjusted to the caring process compared to participants from rural-based hospitals. The children of the participants in this study all received treatment from physiotherapy and, therefore, might not reflect the experience of those who are unable to

access such services. The authors identified this as potentially limiting the depth and breadth of information that could be gained about the caregiver role.

The demands of caring for a child with a lifespan disability such as cerebral palsy increases especially when the children have severe disability and co-morbidities which continue into adulthood (Magill-Evans, Darrah and Galambos, 2011). In a longitudinal study using a mixed methods approach, Magill-Evans, Darrah and Galambos (2011) determined quantitatively caregivers' "scores of measure of life satisfaction, family functioning, and social support change from adolescence to young adult stages of life of their children with multiple impairments; and qualitatively the caregivers' perceptions of the impact of ongoing caregiving on their physical, emotional, work and social wellbeing" (p.184). The study revealed that the concerns of caregivers of children with multiple impairments go beyond meeting the child's special needs during childhood to managing issues of prejudice and stigma in a social context as their children mature to adulthood. The participants (n=21) in this study were interviewed twice when their children were between the ages of 13 to 22 and again when between 20-30 years. The qualitative component revealed that participants had changing views of disability that were informed by the changing needs of their children with cerebral palsy as they grew; that they changed as a person becoming more patient and tolerant over time, and that their view of life changed positively over time. A survey component was also conducted using a life situation questionnaire. The responses indicated that the caregivers' rated their life satisfaction as poor and the mothers' perceptions of the general functioning of their families did not change significantly over time. Support from others, physical impact (back

and knee injuries), and emotional challenges due to ongoing caregiving all increased slightly over time.

Coping with the increased demand of caring for a child with cerebral palsy is directly correlated to physical and psychological health (Carona et al., 2013). According to Lazarus (2006: p. 102) “ coping is the process of cognitive and behavioural efforts to manage demands related to stress and it mainly has to do with the way people manage life conditions that are stressful”. Few studies have explored the positive aspects of the caregiving experience, such as, finding benefit (Green, 2007; Geere et al., 2013). Among the studies reviewed, Green (2007) study used the largest number of participants (n=81) in a mixed method approach to examine the daily hassles, emotional distress and benefits of caring for a child with disability in a developed country (Florida, United States of America). The findings revealed that although caring for a child with disability can be time consuming, expensive and physical exhaustion, but participants expressed valuable benefits in having a child with a disability. In Green’s (2007) study, the participants perceived caring as performing God’s work for which they would receive blessing and they expressed that they felt ‘good in their heart’ despite the physical discomforts and pain they experienced. Similarly, the participants in Gona et al.’s (2010) and Appelbaum and Smolowitz’s (2012) phenomenological study to explore the experiences of 6 fathers of children with severe cerebral palsy indicated that they used spiritual interventions and sharing of experiences with other people as a way to promote and maintain emotional stability. The participants in Appelbaum and Smolowitz’s (2012) study also expressed how their faith in God helped them to cope.

## **2.4 Critical appraisal of qualitative studies reviewed**

Findings from the qualitative studies reflect a broad range of perceptions and an in-depth understanding of varying aspects of the phenomenon being studied. However, it is important to appraise the rigour of the studies reviewed in order to be able to comment on the credibility of the findings and use this information to support the design of subsequent research. Squires (2008: 265) asserted that: “Failure to address language barriers and the methodological challenges they present threatens the credibility, transferability, dependability and conformability of cross-language qualitative research”. Interviews conducted in 10 studies reviewed were conducted in different languages and to ensure credibility, only 8 authors reported that they counter checked the translation for accuracy and consistency, Dalvanda, et al., (2015) was in Persian, Geere et al., (2013) and Gona et al (2010) was in Kenya local languages; Hartley et al., 2005 in Uganda local language; Huang, Kellett and St John, 2010; Scheidegger, Lovelock and Kinèbanian, 2010; Huang, Kellett and St John, 2011; Kuo and Lach, 2012 were in Chinese. Meanwhile Milbrath et al., (2008) in Brazil, and Nimbalkar et al., (2014) in India were silent about the language used for the interviews. However McNally and Mannan’s, (2013) admitted their inability to address the language barriers by using an untrained translator and stated it as a limitation of their study. The authors acknowledged that back translation should be used to ensure congruency between the source and target languages (p. 9). The reason for not using back translation was given as lack of time and resources. To promote trustworthiness, it is recommended that the researcher should acknowledge the co-construction of knowledge role and declare the multiple levels that they are involved in the research process and results (Etherington, 2004; Horsburgh, 2003). Such a declaration will “enhance the

trustworthiness, transparency, and accountability of their research” (Finlay, 2002 p. 211). All the study reviewed gave a description of all the phases of the research process.

Carpenter and Suto (2008) indicated that the explicit description of the methodological approach used in a study is important in justifying the plan of inquiry and promotes coherence as well as consistency of the research design. According to Carpenter and Suto focus groups are often one of the data collection methods used in approaches such as ethnography and mixed methods research. The common methodological approach used (7 out of 17) in the qualitative studies reviewed was phenomenology (Burkhard, 2013, McNally and Mannan’s, 2013; Kuo and Lach, 2012; Appelbaum and Smolowitz, 2012; Huang, Kellett and St John, 2011; Gona et al., 2010; Huang, Kellett and St John, 2010; Hartley et al., 2005,). All the studies indicated that they used phenomenological approach to gain deeper understanding of the meaning of everyday lived experience of their participants. Kuo and Lach (2012, p. 651) justified their choice of phenomenology by stating that this approach “adopts the perspective and patterns that are based on the same essential meaning that participants perceived in different situations over time” and other authors provided similar explanations. One study was identified as ethnography (Scheidegger, Lovelock and Kinébanian, 2010), and two studies used content analysis methodology (Dalvand et al., 2015; Milbrath et al., 2008). The qualitative approaches selected for all the studies were appropriate for the research question and duly justified.

In appraising the quality of qualitative research the process of selecting the participants is very significant and should be tailored to the purpose of the study (Suri, 2011, Jeanfreau and Jack, 2010). Fourteen out of the seventeen studies reviewed used

purposive sampling to consciously select information rich participants and the authors gave sound reasoning for the sampling strategy used. Russell and Gregory (2003) attest that most qualitative studies use purposive sampling techniques to select participants to meet particular criteria for in-depth exploration of a phenomenon.

The sample sizes of the studies ranged from 2 to 51 participants for the qualitative studies, 20, 21 and 81 participants for the three mixed methods studies. Six of the studies indicated that the sample size was informed by the concept of data saturation. A detailed discussion of this concept in relation to sample size decisions and sampling techniques are discussed in Chapter three (Methodology section 3.4.3 page 101). The other studies highlighted that the adequacy of the sample sizes depended on how completely the research question were answered. With the exception of Gona et al. (2010) the participants of the studies reviewed were recruited from a defined group, either from a hospital or community database. Gona et al. recruited participants from a neurological developmental surveillance in a community. Russell and Gregory (2003) point out that the inclusion criteria set by authors for recruiting participants should be appropriate and agree with the characteristics of the methodological approach used. For example, phenomenological studies are aimed at exploring the meanings of experiences as perceived by individuals; hence one of the inclusion criteria of these studies should specify inclusion of people who have intimate knowledge of the phenomenon (Kafle, 2013, Van Manen, 1990). In contrast, although Gona et al. (2010) stated that they used phenomenological approach to explore the lived experiences of caregivers some of the participants were not actually caregivers and so would not have had the direct experience that is of central importance in



phenomenological research. The participants included 20 caregivers, 10 community members who were introduced into the research by the caregivers and 5 teachers who were the teachers of five of the children with disability who were attending school. The purpose of recruiting the community members and the teachers to be part of the study was not documented and was not in conformity with the phenomenological approach used. The authors considered the accounts of other people instead of interviewing only the caregivers who experienced the phenomenon. Although it is significant to report the context in which the participants are experiencing the caregiving process ten of the studies reviewed did not report the geographic location in which the study was conducted. Two specified urban location (Dalvand et al., 2015; Magrill-Evans, Darrah and Galambos, 2011), while two were mixed rural, suburban and urban contexts (Nimbalkar et al., 2014; Gona et al., 2010). Another three focused on rural locations, two in Africa (Hartley et al., 2005; Geere et al., 2012) and one in China (Scheidegger, Lovelock and Kinébanian, 2010).

In-depth interview was the most common data collection strategy used by almost all the studies reviewed which was congruent with the phenomenological approach used in most of the studies. All the authors gave reasonably detailed accounts of the data collection procedure. In qualitative research, the researcher is considered central to the study process, hence researchers both influence and are influenced by the process of engaging in the research (Savin-Baden and Major, 2013; Northway, 2000). Therefore, qualitative researchers are recommended to clearly demonstrate reflexivity, by making explicit their interest in the study topic and the values and beliefs they hold about the phenomenon being investigated, from the conception of the research (Finlay, 2009). Kuo and Lach (2012)

highlighted in their study the significance of bracketing in phenomenology research. The authors provided a detailed account of how the first author engaged in “self-reflection at each stage of the research process to monitor how her own experience of the phenomenon being studied affected the data analysis (Kuo and Lach, 2012, p.651).

## **2.5 Conclusion of systematic qualitative review**

The studies reviewed clearly highlighted the complexity of caring for a child with disability including cerebral palsy. The general consensus in the literature is that quite often one family member, which in most studies was the mother, serves as the primary source of care. Caring for a child with special health care needs increases the stress on the families irrespective of where they live; in a developed or developing country, or in an urban or rural settlement. Qualitative research has been primarily used to explore the phenomenon of the lived experience of caring for a child with cerebral palsy and, in particular, the phenomenological approach. A detailed account of the significance of using a phenomenological approach to explore the experiences of caregivers is described in the methodology chapter. There is a paucity of information about the experiences of caregivers living in rural areas globally including Ghana. Caring for a child in a rural settlement entails many challenges ranging from the absence of adequate health care, limited access to potable water, no electricity and no access to good road networks (Ghana Statistical Service, 2008), which adds to the burden of the caregiving process. Approximately 48% of the Ghana population lives in rural areas. The literature revealed considerable diversity in terms of the caregiving roles and tasks involved and the manner in which caregivers’ embrace and experience the caregiving role in different cultures. This review revealed a

lack of studies investigating caregiving in rural areas in developing countries particularly in Ghana. There is also a need to consider the positive as well as the negative outcomes of the caregiving process and to determine if caregivers of children with cerebral palsy living in Ghana are able to achieve a sense of harmony or equilibrium in relation to their caring roles and responsibilities over the long term. The next chapter presents a detailed description of the methodology used to arrive at the findings and the essential structure of the phenomenon of caring for a child with cerebral palsy.

#### Limitation of the systematic qualitative review

The literature review strategy used in this study was qualitative systematic review method, which allows the flexibility to employ selective or purposive sampling of databases (Grant and Booth 2009, p. 94). Hence some relevant studies of the phenomenon of caring for a child with cerebral palsy may have been missed. With the exception of one study reviewed that did not mention the background of the participants recruited for the study (Dalvand et al., 2015) all the other studies recruited their participants from disability organisations, or clinics or hospitals. Therefore the impact of the support the caregivers received from the facilities could shape their experiences and could be different from caregivers who had never received any support for their children.

There were some methodological weaknesses of the qualitative studies included in this review. Two studies reviewed did not specify the methodological approach used and instead referred to the use of focus groups as the method chosen to collect data (Nimbalkar et al., 2014; Whittingham et al., 2011). Two of the studies reviewed used sampling

techniques that are not commonly used in qualitative studies (Patton 2002). Whittingham et al.'s (2011) study recruited participants from a database through letters and phone calls and Milbrath et al. (2008) randomly selected participants for their study. Both sampling techniques are more commonly used in quantitative studies (Russell and Gregory, 2003).

## **2.6 Review of the Prevalence, Clinical Presentation and Management of Cerebral Palsy**

### **2.6.1 Prevalence of cerebral palsy**

The prevalence of cerebral palsy globally has been estimated to be between 1.5 and 3 per 1000 live births (Cans, 2000). A literature search of studies published between 1965 and 2004, conducted by Odding and colleagues (2006)], revealed that the prevalence of cerebral palsy had risen from about 1.5 per 1000 births in the 1960s to 2.5 to the 1990s. Although this prevalence represents all published studies worldwide, the authors' analysis indicated that there are similarities in prevalence rates between countries. Individual studies conducted in different countries also confirmed these similarities but revealed that the prevalence was higher in developing countries (Yeargin-Allsopp et al., 2008; Wu et al., 2011). Although there are no rigorous studies of the prevalence of cerebral palsy in Ghana, Cerebral Palsy Africa (2014), a non-governmental organisation, has estimated the prevalence to be one in every 300 births. The prevalence of cerebral palsy is estimated to be higher in the near future due to promotion of measures to improve neonatal care. Improved neonatal care may significantly increase the survival rate of premature infants, who would have previously died, and who are at higher risk of developing cerebral palsy (Enweronu-Laryea et al., 2008).

Evidence from studies worldwide reveals that the prevalence of cerebral palsy is associated with race and ethnicity and influenced by social class (Wu et al., 2011; Yeargin-Allsopp et al., 2008; Hammal et al., 2004; Oddings et al., 2006). Yeargin-Allsopp et al. (2008) used a population based surveillance system approach to study 114,897 children in three areas in the United States where people from different races lived. The results revealed that the prevalence of cerebral palsy was higher among black children from Spanish origin than white and among children living in low and middle -neighbourhoods than higher-income neighbourhoods. Maulik and Darmstadt (2007) conducted a systematic review of 41 articles to investigate the prevalence and services provided to children with disability in low- and middle-income countries. They concluded that that there is a dearth of research in the area of childhood disability in low-income countries and a significant lack of information about the magnitude of the burden to individuals and society associated with childhood disability including that caused by cerebral palsy. Idro et al. (2010) confirmed that prevalence rate; types, causes, rehabilitation needs of children with all forms of disabilities and the experiences of their families, are scarcely known in developing countries.

### **2.6.2 Clinical presentation of cerebral palsy**

The clinical picture of children with cerebral palsy portrays a wide range of impairments both physical and cognitive. The clinical presentation of cerebral palsy is a complex combination of pathology and signs and symptoms within the context of an injured developing nervous system (Hirsh et al., 2010; Levitt and Pickering, 2010; Rosenbaum et al., 2007). The result of the injury, which could also include maternal

infection, premature delivery, asphyxia and neonatal jaundice, is overall functional delay and abnormal development which is not static and becomes progressively more severe as more is demanded of the nervous system as the child matures. Cerebral palsy is usually initially suspected when children fail to reach their motor milestones and they show qualitative and objective differences in motor development, such as asymmetric gross motor function or unusual muscle stiffness or floppiness (Levitt and Pickering, 2010). Studies (Ando and Ueda, 2000; Gajdosik and Cicirello, 2002, Wichers et al., 2005; Levitt and Pickering, 2010) conducted over several years have highlighted a number of associated impairments and disabilities resulting from brain damage that negatively influence the levels of functional, emotional, and social participation achieved by children with cerebral palsy. A meta-analysis of thirty studies (Novak et al., 2012) on children with cerebral palsy identified a number of associated impairments; three out of four children experienced some level of pain, one in two had an intellectual disability and one in three had difficulty walking. In addition, a considerable number experienced hip displacement, aphasia, epilepsy, behaviour disorder, urinary bladder control problems, sleep disorders, visual impairments and deafness. A follow up study, conducted over seven years by Opheim et al. (2009) to determine changes in walking function among adults with cerebral palsy, found that balance was the most common factor associated with walking ability over time. Similarly, Burtner et al (2007) observed significant impairment of balance in children with different levels of severity of cerebral palsy when compared with typically developing children. Individuals with cerebral palsy experience higher degrees of chronic pain than the general population and this may result in fatigue and reduced functional ability that could prevent children with cerebral palsy from fully exploring their environment (Engel et al.,

2003; Levitt and Pickering, 2010; Jahnsen et al., 2004). Furthermore, Hirsh et al. (2010), using the first step of a regression model and after controlling for age and sex, found a strong association between social integration and symptoms of vision loss, memory loss and muscle weakness among children with cerebral palsy. Both children and adults with general and specific muscle weakness experience challenges in participating in social activities.

A Dutch population based cross sectional study of the prevalence, presentation and functioning of children with cerebral palsy born between the years 1977-1988 was reported by Wichers et al. (2005) and revealed that the majority (65%) of the children with cerebral palsy studied had cognitive deficits ( $IQ < 85$ ), 40% had epilepsy and 34% had visual impairment. Similar studies in Scotland, England and Canada reported the same sequence and type of co-impairments (Pharoah et al., 1998; Shevell et al., 2009). Krigger (2006) pointed out that intellectual impairment occurs in about two thirds of patients with cerebral palsy and about one half of paediatric patients have seizures. Other co-impairments identified are: hearing defects, abnormalities of speech, perceptual defects or agnosia and dyspraxia as well as behavioural problems and intellectual impairments (Levitt and Pickering, 2010; Krigger, 2006). In spite of these co-impairments the majority of children with cerebral palsy survive until at least early childhood (Hutton and Pharoah, 2006) and according to Levitt and Pickering (2010) these impairments may worsen over time.

Nevertheless, many studies have shown that the survival rates of children with cerebral palsy are high especially among those with mild gross motor function measured using the Gross Motor Function Classification System (GMFCs) and minor cognitive

impairments (Touyama et al., 2013; Westbom et al., 2011; Hutton, Clover and Mackie, 2000). The survival rates identified ranged from 89% to 99%, and those who died were represented by a wide range of ages (5 to 18 years). Westbom et al. (2011) highlighted the high survival rates among children with cerebral palsy. In their study 96% (n=713) of children with cerebral palsy who participated survived to the end of the 10-year study. Other authors studied the survival rates associated with severe cerebral palsy and provided evidence that a considerable percentage (50-42%) of them do live beyond the age of 5 years (Hutton et al., 1994). In as much as these children survive they will need comprehensive rehabilitation to support a productive adult life. There is some evidence to suggest that there is greater proportion of children with severe cerebral palsy in developing countries due to lack of early detection and intervention services (Donald, 2014).

### **2.6.3 Management of cerebral palsy**

The World Health Organization (WHO) defines service delivery as the way inputs are combined to allow the delivery of a series of interventions or health actions (Arnadottir and Egilson, 2012). According to the World Health Report (2000), service provision or service delivery is the primary function required of a national health system. Health systems in developed countries have made services available for the management of cerebral palsy, whilst the health systems in developing countries have yet to address the World Health Report (2000) recommendations. Cerebral palsy is a condition that cannot be cured but can be managed (Levitt and Pickering, 2010). The goals of management are to promote functional capabilities and performance, to prevent secondary impairments and, above all, to increase a child's developmental capabilities through the use of appropriate



combinations of interventions (Kriger, 2006). The interventions may include developmental, physical, medical, surgical, chemical, and technical modalities. In physical, occupational, speech, and behavioural therapies, the goals of service delivery include enhancing patient and caregiver interactions while providing family support (Kriger, 2006). Optimal treatment for children with CP therefore requires a multidisciplinary team approach (Levitt and Pickering, 2010).

Globally, children diagnosed with cerebral palsy are referred for rehabilitation care, which is delivered through different approaches (Odding et al., 2006). The approaches are informed by the complexity of the clinical presentation and variety in functional challenges faced by the children (Rapp et al., 2000). Many of the conventional approaches used in treating developmental conditions target primarily physical impairments of gross and fine motor function with emphasis on functional activities (Odding et al 2006; Levitt and Pickering, 2010). In the process of planning interventions and selecting approaches for care delivery, the inclusion of non-clinical behavioural, emotional, cultural and social issues has been strongly advocated (Raina et al., 2005; Levitt and Pickering, 2010).

Many studies have provided evidence of the effectiveness of early, well-coordinated, comprehensive, caring rehabilitation for children with cerebral palsy (Levitt and Pickering, 2010; Rosenbaum, 2003). Rehabilitation service provision for children with cerebral palsy is a major facilitator in their achieving a productive independent adult life. The burden of caregiving is lessened when the child receives rehabilitation interventions. In situations where the primary caregivers of children with disability have no access to rehabilitation services or, in many cases, any form of health care, the families themselves

develops strategies to support their child to achieve their optimal function (Brotherson et al., 2008).

Management of cerebral palsy still remains a major challenge in developing countries. A recent report from the medical conference proceedings involving doctors from 22 African countries including Ghana revealed that: “guidelines for management of cerebral palsy from developed countries were often poorly transferable in terms of both content and relevance to the reality of countries with overburdened medical systems and where many patients live in remote and widely scattered settlements with poor road and infrastructure and limited access to investigations and medications” (Donald et al., 2014, p. 7). The group recommended more evidence-based clinical studies to investigate the efficacy of home-based interventions. Physiotherapy services are the only rehabilitation services being delivered to children with cerebral palsy who visits the tertiary institution.

#### **2.6.3.1 Physiotherapy Intervention for Children with Cerebral Palsy**

Conflicting and inconsistent opinions are expressed about the intensity, duration, type, and frequency of physiotherapy interventions for children with CP (Anttila, 2008). The decision about an appropriate therapy intensity for acquisition of significant motor skills in children with CP greatly depends on diversity in the level of severity and the age ranges of the population under study (Shamir et al., 2012), associated co-impairments, and diverse family needs (Masri et al., 2011). Factors that inform the frequency and duration of physiotherapy are the profile of the children with CP such as age, family socio-demographic characteristics and the routine and practices of the facility in which the care

is delivered (Mazer et al., 2006), availability, affordability and type of intervention (Majnermer et al., 2002; Weindling et al., 2007).

The intensity of physiotherapy is the focus of a number of studies in terms of the duration and frequency but not the detailed handling and manipulative skills (Christiansen and Lange, 2008; Ustad, Sorsdahl and Ljunggren, 2009; Yabunaka et al., 2011). These studies had a similar definition of intensity as duration of 50-60 minutes per session and frequency of 4-5 sessions per week. However, a frequency of physiotherapy sessions once or twice per week is considered to be inadequate (Christiansen and Lange, 2008; Yabunaka et al., 2011). According to Bailes and Succop (2012) the number of physiotherapy sessions received was significantly predicted by the functional level determined by the GMFM, age, and the type of insurance. This study reviewed a retrospective electronic medical record of children with cerebral palsy (n=425). The authors identified, after multiple comparisons for each variable in the final model of multi-way ANOVA, that a greater than average number of therapy sessions were received by children with functional levels of GMFM of II, III, IV than V, in individuals aged less than 5 years compared with those older than twelve years, and more in those having private insurance than public insurance. Although their study was conducted in only one geographical area, its uniqueness in finding the significance of type of insurance as a predictor of number of physiotherapy sessions received is worth noting.

There is no convincing evidence to support any type and length of therapy for children with cerebral palsy, (Shamir et al., 2012; Brown and Burns, 2001). The quality and level of evidence derived from a randomized clinical trial, which was assessed using

the Jadad scale (Jadad et al., 1996) and Sackett scale (Sackett 1989) respectively, indicated that high frequency physiotherapy intervention is effective irrespective of the type (Odman and Obeng, 2005). Meanwhile, Bower et al. (2001) did not find any significant benefit of long-term intensive physiotherapy and stated that the effectiveness of the treatment can be increased when it is focused on one central goal. Shamir and his colleagues (2012) examined the effect of intensive intermittent physiotherapy on one central goal that of acquiring sitting balance among children with CP with age range of 12 to 24 months. They concluded that the regimen yielded a mean improvement of 7.8% as compared to 1.2% with the standard treatment. The choice and type of physiotherapy modalities used in the treatment plan of children with CP is informed by the focus and goal of the intervention and most importantly where the therapy is delivered as well as the experience of the therapist (Palisano et al., 2012, Levitt and Pickering, 2010). There is no scientific evidence to prove the effectiveness of one method over another and a diverse approach is often adopted to meet an individual child's needs (Rosenbaum, 2003). Palisano et al., (2012) explored the focus and amount of physiotherapy and occupational therapy delivered to children with CP and stated that the level of gross motor function determined the focus of therapy. In their study interventions for children with severe impairment of motor function (GMFCS Level of IV-V) were focused mainly on the primary impairments, those who were GMFCS Level of II-III treatment was focused on activity, environmental modifications, prescription and usage of assistive devices. In contrast, the treatment of children with mild CP (GMFCS of I) was focused principally on self-care.

Physiotherapy treatment of children with CP consists of conventional techniques

like exercise therapy, manual stretching, massage, and others as well as approaches derived from motor learning based theories such as Neurodevelopmental Treatment (NDT), muscle education and braces, progressive pattern movements, and synergistic movement patterns (Levitt and Pickering, 2010). Many different treatments for cerebral palsy are currently available, however, each case of cerebral palsy is as unique as the individual it affects (Rosenbaum 2003). A systematic review of common physiotherapy interventions for children with cerebral palsy revealed strength training to be the most studied intervention and that was also supported by the strongest evidence (Martin, Barker, and Harvey, 2010). Children with cerebral palsy often develop muscle weakness; therefore strength training had been incorporated in most treatment protocols (Damiano, Dodd, and Taylor, (2002). However, the effectiveness of strength training is disputed by a recently conducted meta-analysis (Scianni et al 2009). This study sought to systematically review pooled data of five randomized control trials on effectiveness of muscle strengthening interventions in children and adolescence with cerebral palsy, and whether or not it is harmful in the sense of increasing spasticity. They found that strengthening interventions did not significantly increase the strength or activity levels of participants nor did it increase spasticity. They were of the view that the strengthening interventions were of shorter duration and lower intensity, and again none of the studies was consistent with the intensity prescribed by the guidelines of America College of Sports Medicine (2000). This controversial conclusion has resulted in a discussion within the profession on the efficacy of strength training for children with cerebral palsy. Recently a meta-analysis of four Randomized Control Trials (RCTs) focusing on resistance training of the lower extremities by Veschuren et al. (2011) concluded that, although there was a small increase in strength for the intervention groups,

there was no statistical significant difference between the intervention groups and the controls. Veschuren et al. (2011) observed that the RCTs they reviewed did not adhere to the guidelines prescribed by The National Strength and Conditioning Association (NSCA) in Faigenbaum et al. (2009). They further suggested that although the NSCA guidelines were developed for resistance training in normally developing children they could serve as a starting point for prescribing resistance training programs for children with cerebral palsy. They recommended further research to ascertain how muscle strength increases among children with cerebral palsy and to develop evidenced based guidelines.

The predominately used treatment approach, based on motor learning theory, is Neurodevelopmental Treatment (Brown and Burns, 2001). Karl Bobath, a neuropsychiatrist, and Berta Bobath a physiotherapist first introduced the Neurodevelopmental Treatment (NDT.) approach utilising inhibition and facilitation development in the 1940s, and this has commonly been incorporated into rehabilitation programs for children with cerebral palsy over the intervening years (Brown and Burns, 2001, Butler and Darrah, 2001). The treatment approach, known as NDT or the Bobath approach, aims to establish normal motor development that will improve functional movement by facilitating normal sensorimotor components such as muscle tone and reflexes or by inhibiting abnormal movement patterns (Bobath and Bobath, 1952; 1972; Butler and Darrah, 2001). The NDT approach has been shown to be effective in improving gross motor ability, postural control and stability of children with cerebral palsy (Ketelaar et al., 2001; Tsorlakis et al., 2004). Tsorlakis et al. (2004) conducted a randomized control trial to investigate the effect of intensive NDT in gross motor function of children with

cerebral palsy. The authors concluded that NDT increased the gross motor function of the study subjects but the increase was significantly higher in those who had a greater intensity of therapy.

The management of cerebral palsy in general have proven effective in improving the functional capacities of children with cerebral palsy. Caregivers of children with cerebral palsy will have an improved quality of life if their children's functional capacities are improved and they become independent. Hence the justification of this study goes beyond novelty of it in Ghana, but will serve as the basis for physiotherapist and other rehabilitation professionals to plan treatment intervention for new clients reporting to the hospitals and future establishment of community based interventions.

## **Chapter 3**

### **Methodology**

#### **3.1 Introduction to chapter**

This chapter presents the methodological approach I used to explore and describe the meaning of lived experiences of caregivers caring for children with cerebral palsy in rural Ghana who have never received any form of rehabilitation. The first part of the chapter discusses the choice of methodology, that is, phenomenology and descriptive phenomenology that guided the research design and process. The second part offers a detailed description of the study design, including sampling strategy, participant recruitment, data collection procedure, ethical considerations, data analysis process and the reflexive approach used in the study.

#### **3.2 Choice of methodology**

Both quantitative and qualitative approaches are valid and useful though they give diverse conceptualization of the truth (Clark, 1997). The research problem, the questions raised and the researcher's philosophical and paradigmatic perspectives inform the choice of research methodology. The participants in this study are individual caregivers of children with cerebral palsy, living in poor rural communities, deprived of basic amenities such as potable water, quality health care for their special needs and general good environmental conditions. Amidst all these challenges, caregivers of children with cerebral palsy have the extra burden of caring for children with special needs, which may not be similar to caring for a typical child. The research question was 'how individuals who care



for children with cerebral palsy in a rural Ghanaian context, but who have not received any form of rehabilitation, experience the caregiving role’?

Initially I took a philosophical stance based on the characteristics of the phenomenon being studied, what could be known about it, and how and when the knowledge could be attained (Creswell, 2007). What can be known gives rise to the ontological question what is the nature of the reality and how and when knowledge can be attained is informed by the epistemological question what is the nature of knowledge (Blaikie, 2007). As Creswell et al (2007, p. 238) suggest, it is important that researchers begin their inquiry process with an examination of the “philosophical assumptions about the nature of reality (ontology), how they know what is known (epistemology), the inclusion of their values (axiology) and the nature in which their research emerges (methodology)”

To begin the inquire process as recommended by Creswell et al., (2007), I started by reviewing the ontological theories found in literature. Two main ontological theories have been stipulated in the literature about the nature of reality: idealist and realist (Collier, 1995; Blaikie, 2007). Both these theories highlight the existence of some kind of reality but differ from each other in determining whether reality is independent or dependent of the individual mind. Ontological views of realism are objective in nature whereas those of idealism are subjective. Realism suggests that there is objective knowable knowledge of the world that is independent of the mind. On the contrary, idealist ontology claims that, “the external world consists of representations that are creations of the individual mind” (Blaikie, 2007, p. 16). The experiences of caregivers of children with cerebral palsy would

be different from each other although the social context could be similar. The influence of the social context on each individual could be unique and may differ due to their personality, perceptions and beliefs. Hence the idealist perspective corresponded with the phenomenon being studied.

From an idealist perspective epistemology “is a way of understanding what, and explaining how, we know what we know” (Crotty, 1998, p. 3) and examines the nature of knowledge as well as the relationship between the researcher and what is being researched. Two key philosophical systems or theoretical paradigms, that is, objectivism and subjectivism, address the ontological and epistemological questions raised in research and relate to researchers’ different worldviews (Crotty, 1998; Creswell, 2007; Blaikie, 2007). The researcher’s worldview and relationship with what is being investigated are discussed in contrasting terms within these two systems. In objectivism the researcher views the object being studied as already existing and as independent of consciousness. The role of the researcher is to discover ‘the’ truth about that object. In contrast, in subjectivism knowledge development – understanding of the object of interest – assumes there are multiple realities or ‘truths’ and is a joint endeavour between the researcher and participants. According to Munhall (2007, p. 161), the world is knowable only through the subjectivity of being in the world.

The process of choosing the methodological approach for this study was by considering both the philosophical and paradigmatic assumptions of both quantitative and qualitative research. After considering the ontological and epistemological assumptions, I

determined that ontological idealist stance and epistemological subjectivism best fit my own worldview and was congruent with the research purpose.

Theoretical paradigms are characterized by a combination of associated epistemological, ontological and methodological assumptions that make logical sense (Blaikie, 2007). The combination of different sets of ontological and epistemological assumptions characterizing different paradigms influences the choice of research methodology and methods. For the purpose of this discussion, methodology can be defined as: a specific philosophical and ethical approach to developing knowledge, a theory of how research should, or ought, to proceed given the nature of the issue it seeks to address” (Hammell, 2006, p. 167). Research methods, in contrast, are defined as the techniques used to collect and analyze data in order to describe or explain the characteristics of phenomena (Blaikie, 2007). Qualitative and quantitative research methodologies represent different ways of looking at the world, and adopt different techniques in order to project divergent assumptions (Crotty, 1998). It is essential that researchers demonstrate an understanding of the distinction between interpretivism (associated with qualitative research) and positivism (quantitative research) in order to justify the application of the appropriate methodological theory to the research process as this contributes to a coherent design and rigorous analytic process (Carpenter & Suto, 2008)

### **3.2.1 Philosophical and paradigmatic assumptions of quantitative research**

Quantitative research methods have their own set of assumptions and are generally informed by scientific paradigm of positivism, which entails direct manipulation of variables, observation and measurement. Knowledge in the positivist paradigm is characterised by what is discovered, “rather than something which is produced by humans, and researchers gain knowledge by identifying the facts” (Savin-Baden and Major, 2013: p. 19). The purpose or aim of inquiry in the positivist paradigm is to measure, quantify or describe an extent to which a reality can be known with the ultimate intent of predicting and controlling the phenomena (Creswell, 2007). Positivism is based on the assumption that a single truth can be proved objectively, is independent of the mind and can be revealed through hypothetical deductive procedures (Crotty, 1998).

Globally, medical research uses quantitative approaches to make scientific inferences about health care delivery, the efficacy of modalities and generate evidence to support standards of care. In issues concerning caring for children and childhood, the positivist research paradigm provides rigid control of variables and enables translation of findings into universal principles and generalization (James, 2001). However, in considering only the knowledge obtained from scientifically measurable and quantifiable facts, issues can often be understated or taken out of context and the holistic nature of caring for children and childhood could be lost (James, 2001). The complexity of caring for a child, especially a child with special needs, will be lost if research focuses solely on the use of reliable and valid outcome measures or instruments and ignores subjective

experience. Crotty (1998: p27) affirms that: “subjective understandings may be of very great importance in our lives”. Critics (for example, Crossan, 2003) of positivism argue that a rigorous quantitative approach, such as, a randomised controlled trial provides only a superficial view of the phenomenon being studied and addresses research questions related to proving a hypothesis or establishing cause and effect relationships between variables.

### **3.2.2 Philosophical and paradigmatic assumptions of qualitative research**

Qualitative research “has no theory or paradigm that is distinctly its own” (Denzin & Lincoln 2005, p. 22); rather it is informed by a number of philosophical systems or paradigms e.g. interpretivist. An array of paradigms, informing qualitative approaches, is identified in literature. For the purpose of this study, two paradigms, post-positivism and constructivism, are discussed in the next section. Post-positivism is like positivism in that it an overarching philosophical system that underpins the ‘multiparadigmatic nature’ of qualitative research and constructivism is one of those paradigms. The choice of a paradigm is based on the philosophical assumptions that underpin it, and which are in agreement with the theoretical influence of the study and the philosophical stance taken by the researcher.

#### **3.2.2.1 Post-positivism**

Post-positivism is based on the belief that participants hold multiple perspectives of social reality and that these can be known through logically related steps of inquiry (Creswell, 2007). Historically post positivism arose as a response to the dominance of

positivism. It has elements of reductionism (characteristic of positivism), an emphasis on empirical data collection, and determinism. It holds the philosophical position that complex phenomena can be explained in terms of relations between the constituent phenomena. There are many variable and multiple realities, which might not be true, relevant or meaningful for all persons. Ontologically, qualitative research, using a belief system grounded in post-positivism, assumes that realities must be subjected to critical scrutiny, practically using rigorous methods of data collection and analysis to facilitate an understanding of the diversity of realities (Blaikie, 2007). Post-positivists hold the view that “realities of the world cannot be viewed free from any influence of observer’s view point” (Crotty, 1998, p. 40). The assumption is that investigations of these realities have been “basically flawed with human intellectual mechanisms and the phenomenon can be flawed by the researcher’s assumptions and beliefs (Guba and Lincoln, 1994, p163). Consequently, Guba and Lincoln (1994) advocated that post-positivism assumes that it is possible to approximate reality but never fully know it. Methodologically, post-positivist research employs an ‘emic’ (or insider) approach of how people perceive or categorize the world to assist in determining the meaning and purpose that people ascribe to their action (Denzin and Lincoln 2005). In assuming an ‘emic’ approach, the researcher puts aside previous knowledge and assumptions in order the perceptions and meanings of the participants can prevail (Savin-Baden and Major, 2013).

### **3.2.2.2 Constructivist paradigm**

Constructivists are committed to the notion that knowledge and truth are created and not discovered (Schwandt, 1994). Ontologically, constructivists hold the assumption

that reality is a product of one's own creation and reality cannot be separated from the knowledge of it (Savin-Baden and Major, 2013). Individuals create or construct an understanding of reality in the context in which they operate, and through interaction with their environment. They also have the ability to express and articulate it to others. Constructivists seek to undertake research in the natural setting (Guba and Lincoln, 1981; 1994; Guba, 1990) and "share the goal of understanding the complex world of lived experience from the point of view of those who lived it (Schwandt, 1994, p.118). The researcher is positioned to examine in detail the experiences of people as they live and interact within their own environment. Epistemologically, constructivists suggest that: "knowledge is a compilation of human-made constructions" (Raskin, 2002, p.4) and knowledge is built through increasingly nuanced constructions of individual and shared group experiences (Schwandt, 1994). The source of knowledge is the subjective view and the meanings that participants attach to their experience. Hence the meanings are not discovered but constructed. This paradigm embraces the belief that people attribute meanings to realities, phenomena and situations they experience through the complex processes of social interaction (Schwandt, 1994). Since there are numerous components of social entities, the interplay between individuals and their worlds helps to form, alter, and develop the constructions of reality or the phenomena. Therefore reality is viewed as pluralistic, which includes diverging and conflicting views.

Another version of constructivist philosophy is social constructivism, which was articulated by Kenneth and Mary Gergen (Gergen & Gergen, 1985). A clear distinction of the two versions of constructivism was provided by Schwandt (1994, p. 127) who said: "

constructivism refers to the meaning –giving activity of the individual mind, to cognitive processes, while social constructivism refers to inter-subjectively shared knowledge, meaning-giving that is social rather than individual”. As individuals come into relationship and interact with others in their social world and unique environment, they not only respond to, and interpret each other’s actions but also construct meaning or common interpretations of aspects of their reality. Smith and Deemer (2000) consider that differing perspectives do exist although these do not have the same value but all need to be examined in detail, and revealed through exploration and investigation.

The methodology of constructivism is hermeneutical and dialectical (Guba and Lincoln 1994). Hermeneutical in the sense that the aim is to understand what people say, do and why they do it, and dialectical because logical discussion is used to present the essence of the phenomenon being studied (Denzin and Lincoln, 2005). In terms of practice, researchers who espouse the constructivism paradigm ask broad and general questions in an attempt to give participants the opportunity to construct the meanings they attribute to the phenomena being studied (Creswell, 2007). The constructions that emerge from these studies are unique for a particular phenomenon and social context and may never be repeated in exactly the same way.

### **3.3 Rational for choosing a qualitative approach**

Over the past two decades the use of qualitative approach has gradually increased in medical research. Qualitative methodology in the medical field is a feasible and legitimate approach to developing a comprehensive understanding of the social aspect of issues pertaining to prevention of illness, process of care delivery, recovery processes and



rehabilitation (Creswell, 2007; Pope and Mays, 2008). “Qualitative inquiry represents a legitimate mode of social and human science exploration, without apology or comparison to quantitative research” (Creswell, 2007 p.11). Accordingly the subjective data derived from qualitative inquiry are equally important as the objective inferences in health care planning, delivery and evaluation.

The recent publications of qualitative studies in high impact factor medical journals like *The Lancet*, *The British Medical Journal*, *Journal of American Medical Association* and others give a good indication of the acceptance and legitimacy of qualitative approaches in health care including rehabilitation and evidenced based practice (Gibson and Martin, 2003). An early example was Carpenter’s (1994) study which highlighted the significance of using a qualitative approach in rehabilitation research among individuals with spinal cord injury to reveal their perceptions and interpretations of realities of their worldview. Realities should be explored because the individual behaviour and their perceptions of the process of care will depend largely on how they make meaning of their reality. Central to the qualitative approach is the assumption that multiple realities exist to be explored and these can be derived from the perceptions and meanings co-constructed by the researcher, the individuals being investigated, and the readers or audience interpreting the results of the study (Denzin and Lincoln, 2005)

The selection of qualitative inquiry depends on a number of factors that have been elaborated by numerous authors (Creswell, 2007; Creswell and Clark, 2007; Jensen et al., 2000). Qualitative research is used when there is the need to explore or get a detailed and in-depth understanding of a problem or an issue that cannot be found in predetermined

information from literature or as a result of previous studies. Therefore, the final report or the product of qualitative inquiry includes the voices of participants, multiple sources of data and the reflexivity of the researcher which can be presented in the form of a report, narrative, tale, themes, or theoretical construct (Greenfield et al., 2007). A combination of information enables a in-depth description and interpretation of a complex problem, which will, in effect, extend the available literature or signal the need for action (Creswell, 2007). Choosing a qualitative inquiry will also empower the participants to share their stories, as they understand their unique individual experience, which would not be possible using quantitative research approaches. Finally qualitative researchers seek to collect data in the participants' unique setting, that is, where they experience the phenomenon of interest, and throughout the research process the researcher focuses on learning how the participant interprets the problem and makes meaning of it (Creswell, 2007). The discussion above informs the choice of qualitative approach for this study. After choosing qualitative inquiry, a decision was made on the choice of specific methodological approach. In Creswell's (2007) opinion qualitative researchers are confronted with a confusing number of qualitative methodological approaches to choose from. A phenomenological approach of inquiry was chosen as the most appropriate to address the purpose of this study.

### **3.3.1 Phenomenological Approach to Inquiry**

Moran and Mooney (2002, p.1) describe phenomenology as a “study of whatever appears to consciousness, precisely in the manner in which it so appears.” that is, getting to the essence of the meaning individuals make of their experiences. “Meanings” as stated by Krauss (2005, p. 762) “are the linguistic categories that make up a participant's view of

reality and with which actions are defined”. Human beings have the ability and instinct to understand and make meanings of their own lives and experiences. The conscious expressions of life experiences generate meanings (Chen, 2001). Finlay, (2009 p. 474) described phenomenology as “an umbrella term encompassing both a philosophy and a range of research approaches”. Two main phenomenological approaches that are most evident in the literature - descriptive (eidetic) phenomenology, which focuses on the tradition of Husserl, and interpretive (hermeneutic) phenomenology, based on the tradition of Heidegger (Finlay, 2009). A critical appraisal of Husserl’s approach to descriptive phenomenology is made in the next section to establish the choice of this approach for this study.

### **3.3.2 Descriptive Phenomenology**

Edmund Husserl (1859-1938) was a mathematician, who was the founder of experimental psychology and devoted his life to philosophy. Husserl’s philosophical ideas began as a reaction to the use of methods of natural science and developed into descriptive phenomenological approach to inquiry (Blaikie, 2007). According to Savin-Baden and Major (2013) “Husserl founded phenomenology on the basis that what needed to be examined was the way people lived in the world, rather than the world being seen as a separate entity from the person” (p 213). Descriptive phenomenology is a philosophical approach that examines the foundation and status of knowledge as well as the relationship between the knower and the known (Blaikie, 2007). Two major concepts are associated with the practice of descriptive phenomenology; life- world, which is also discussed as, lived experience and essence. Husserl used the concept of life world to indicate

experiential happenings that become conscious and it is based on the assumption that there is value in the conscious lived experiences perceived by humans. Human motivation and action is influenced by what is perceived to be real. The concept of essence indicates that there are invariant structures that exist within the phenomenon being experienced that make it what it is. In effect, it suggests that there are similar features, which are referred to as universal essence or eidetic structures, in the perception of all persons who experienced a specific phenomenon ((Lopez and Willis, 2004). Todres (2005) suggested that the term essence thus refers to the “qualities that give an experiential phenomenon its distinctiveness and coherence; the qualities that make something what it is as it appears relationally to consciousness” (p.105). Some essential features can be general while others can be specific, context and social bound. According to Todres (2005), the descriptive phenomenological research approach has a number of unique components: “the researcher gathers detailed concrete descriptions of specific experience from others; the researcher adopts the attitude of the phenomenological reduction in order to intuit the intelligibility of what is given in the experience; finally, the researcher seeks the most invariant meaning for a context” (p. 107).

The primary focus of the phenomenon of interest in this study was the process of caring for a child with a chronic disabling condition who had never received any form of rehabilitation. My background (discussed in detail in the Reflexivity section of this chapter) lead me to be concerned about how children with cerebral palsy were being cared for by their respective primary caregivers and, more importantly, how these individuals attributed meaning to the caregiving experience as well as the support system available to

them. Secondly, I believed that the unique cultural and social values of the caregivers deserved to be recognised and better understood in terms of their influence on the caregiving experience and role. These concerns and beliefs influenced my choice of descriptive phenomenological approach. I believe that the concrete unique meanings that caregivers give to the caregiving process can be discovered and described but, as discussed by a number of authors (for example; Giorgi, 1997; Giorgi and Giorgi, 2003; Moustakas, 1994; Todres, 2005), this required me to ‘bracket’ my values and suppositions.

My assumption that the consciously perceived experiences of caregivers have value and can be an object of scientific study is based on Husserl’s philosophy. I believe that the conscious information given by the participants will add to the professional knowledge base and will benefit health professionals who are seeking to understand caregivers’ motivation and actions, which are influenced by what they perceive to be real. My assumption that the essential features in the lived experience of caring for a child with cerebral palsy are similar to all persons who have lived the experience reflects Husserl’s descriptive phenomenological approach. Husserl recommends that researchers look beyond their constructions, preconceptions and assumptions to describe only the essence of the experience being investigated (Gearing, 2004). Preconceptions and assumptions are natural attitudes inherent in human nature but should not be used to prejudge what is being observed and described in a study. The researcher must attempt to “bracket” any assumptions, perceptions or understanding about the phenomenon of interest in order that it might to speak for itself through the participants (Crotty, 1998). The research approach involved a careful examination of the caregivers’ experience, how they understood their

own experience and through the interview process, empowered them to identify the essential qualities of their experience. Raskin (2011) described psychological essence as “the ways people understand and interpret themselves in the light of their decisions” (p.228). The essences people know are the products of how they have structured and organized their experience and can be revealed through their conscious actions. Being focused on determining the actual lived experience of caregivers’ was fundamental to Husserl’s philosophy and has guided the process and completion of this study.

### **3.3.2.1 Descriptive Phenomenology and Physiotherapy/ Rehabilitation Research**

The increase in global burden of chronic disabling conditions and non-communicable diseases especially in developing countries calls for target rehabilitation care according to the needs of the people in unique communities (Kumar, Roy, and Kar, 2012). Phenomenological research offers an in-depth description of the lived-experiences of both therapist and the clients to build more sensitive and appropriate rehabilitation care. According to Shaw and Connelly (2012, p. 401) descriptive phenomenology resonates more with a biomedical approach to science that seeks to bracket presuppositions about research problems in order to achieve objective results that apply across contextual boundaries”. In developing or enhancing physiotherapy practice in an environment with limited resources the treatment should be more specific and efficient addressing the needs of the client. Descriptive phenomenological approach will bracket any confounding factors and allow the experiences and perceptions of client about their rehabilitation needs, compliance to treatment schedules, and highlight clients’ objective understanding of the rehabilitation practice in general. A number of physiotherapy based research have

recommended the use of descriptive phenomenology approach “to observe and identify the phenomenon being experienced free from personal biases” (Therkleson, 2010, p. 2226; Shaw and Conelly, 2012; Igo, 2014). Hence the use of descriptive phenomenology in physiotherapy practice is highly recommended. The experience gained in using descriptive phenomenology approach for this study is highly appreciated. The skill acquired would be utilised in the near future in developing and evaluating rehabilitation programmes.

### **3.4 Study Design**

This study was designed to conform to the common characteristics of descriptive phenomenological approach, with the intention of understanding and describing the essence of the meaning caregivers’ ascribe to their experiences of the phenomenon of caring for a child with cerebral palsy, who has never received any form of rehabilitation. I was convinced that a deeper understanding of individual’s common or shared experiences of the phenomenon would inform the basis of developing a suitable and affordable rehabilitation model for children with cerebral palsy living in deprived areas. To ensure good quality and being mindful of the necessity to achieve trustworthiness, this section outlines the sampling strategy, sample size, and recruitment of participants, data collection procedure and ethical considerations.

#### **3.4.1 Sampling Strategy**

The process of selecting the participants in qualitative research is of central importance; it needs to be legitimate and tailored to the purpose of the study (Suri, 2011, Jeanfreau and Jack, 2010; Patton, 2002). This study aimed to generate a rich narrative

description of the phenomenon of caring for children with cerebral palsy from the perspective of people experiencing the phenomenon. Hence a purposive sampling approach was used which involves deliberate choice of participants based on the inclusion criteria set for the study and their ability to share their experiences. Patton (2002:230) defines purposive sampling as “selecting of information –rich cases, those from which one can learn a great deal about issues of central importance to the purpose of the inquiry.” Patton (1990) affirms that this sampling strategy can be justified because of the subjective, in depth nature of the data acquired from small samples. Qualitative researchers acknowledge that some informants can provide deeper insights and understanding of their experiences than others (Marshall, 1996). The advantage of purposive sampling is to select informants who can provide the desired information and, as a consequence, small samples are most commonly utilized. Participant selection is primarily based on the judgement of the researcher and, as a result, the data collection could be compromised, involuntarily or voluntarily, due to informants’ desire to please or meet the presumed expectation of the researcher. Therefore, in this study other forms of data were collected including field notes, a reflective dairy and member checking to promote the credibility of the interview data.

Sampling decisions were made according to some predetermined broad inclusion criteria as shown in table 3.1. The definition of caregiver used in this study was “non- paid individuals who are primarily responsible for providing and /or coordinating care for children with cerebral palsy in the home, such us mother, father, sibling, other relatives, and non-relative caregiver such as friend or neighbour” (Cho, 2007:24). The challenge of



using this definition was the description of ‘primarily’. Therefore a further explanation was made to include individual who is responsible in assisting the child with cerebral palsy with activities of daily living including grooming, feeding, bathing, toileting and responsible for the general well-being of the child. Hence individuals invited to participate in the study had to conform to that definition. Participants were required to live, and provide caregiving, in the rural community and have cared for the child for at least six months. In addition, to explore the experiences of caregiving fully, participants needed to be able to speak and express themselves fluently in the Akan (Twi) or Ga languages. I am fluent in the Ga language, which is my mother tongue, and 6 dialects of the Twi, or Akan language.

**Table 3.1 Inclusion and exclusion criteria set for the study**

No.	Inclusion criteria	Exclusion criteria
1	Individuals who met the definition of caregiver stated by (Cho, 2007:24) for the past six months	Individuals who qualify by the definition of caregiver but having cognitive challenges were excluded
2	Resident in the rural community for the past six months	
3.	The individual was fluent in speaking Akan or Ga	

The purposive sampling approach was initially used but, as the study progressed, a snowball sampling approach was introduced by which some of the participants suggested other people they knew who were also caring for children with cerebral palsy. A snowball sampling approach is a linear, non-probability sampling technique that is used to recruit potential participants for studies where potential participants are hard to find (O’Byrne and

Holmes, 2008). This approach overcame my concern that some carers of children with cerebral palsy might not volunteer to be involved for fear of stigmatization

### **3.4.2 Participant Recruitment**

The idea of where to locate the participants of this study originated from a situational analysis of Primary Health Care on prevention, early detection and intervention of childhood disability in the Shia-Osudoku district (Nyante, Baltussen and Asante, 2012). A summary of the study is provided below to highlight the background of the recruitment of the participants. Shia Osudoku district is one of the Ten (10) Districts in the Greater Accra Region of Ghana. It forms about 41.5% of the landmass of the Region and is therefore the largest. The district is divided into two sub-districts namely Dodowa and Osudoku. The health facilities available in this district are 1 District Hospital, 2 Health Centers, and 13 Community-Based Health Planning and Services (CHPS) zones. A Non-Governmental Organisation, Christian Blind Mission (CBM) based in Germany, sponsored the study. CBM is an international Christian development organization, committed to improving the quality of life of people with disabilities in the poorest communities of the world.

**Table 3.2 A summary of the situational analysis study**

The main purpose of the study was to assess the implementation strategies for prevention, detection and intervention of early childhood disability being carried out at the Primary Health care delivery level. Furthermore to assess the knowledge of midwives and community health nurses on prevention, early detection and intervention of early childhood disability.

The study uses document review, qualitative and quantitative approaches to answer the research question. For the document review, available policies on the childhood

disability were retrieved from the Ghana Health Services (GHS), Child welfare Organizations, and other Stakeholders working with GHS. For the qualitative 10 health professionals in-charges of midwifery and child health clinics in primary health care facilities were purposely selected and interviewed. For the quantitative aspect, 80 Community Health Nurses working in the child health clinics in the selected Primary Health Care gave their responses on knowledge about childhood disability questionnaire.

The study revealed general knowledge and practices focusing on screening and early detection of childhood disability especially physical were limited. It was also revealed that there are no multidisciplinary screening programs in place in the whole district. The major challenge identified was in the issue of early intervention. Knowledge of how to intervene by simple community devices was very low. Participants confirmed their lack of knowledge on how to detect and intervene for childhood disability especially Erb's palsy and cerebral Palsy in the community.

After the research, a training workshop was organised for the community health nurses on prevention and early detection of childhood disability sponsored by CBM international.

The Community Health Nurses (CHS) that took part in the workshop revealed they had identified some children in the selected communities who were suspected to have cerebral palsy, but were not receiving any form of rehabilitation. The only health professionals attending to these children were CHNs. Therefore, initially, participants of this current study were identified through the situational analysis. Due to the rural focus of the research, recruitment of participants was centred in five selected CHPs zones and not the hospital or health centres. I scheduled a meeting with all the CHNs in each facility (the five selected CHPS zones) as a group in their offices. Each CHPs zone had three CHNs

providing primary health care to the community. The CHNs are the only health professionals who do home visits in their respective catchment areas and could identify families with children with cerebral palsy. At these meetings the aims and objectives of the study were explained in detail to ensure that each CHNs had a comprehensive understanding of the study. The CHNs identified, invited and distributed a flyer (see Appendix 1) to caregivers of children who had been suspected of having cerebral palsy in their CHPs zone and their caregivers who met the established criteria, to participate in the study. The caregivers, who wished for further information or were willing to participate in the study, were asked to contact the CHNs in their area or the researcher, whose contact details were on the flyer, for further details.

. The recruitment process was complex and required considerable thought and consultation with the supervisory team. The rural communities in the region, and the households within each community, were located long distances from each other. Households did not have numbered addresses nor was there a systematic record of their locations, therefore, I had to depend on the community health nurses, and a special education teacher introduced to me by the CHNs, to assist in locating the homes of potential caregiver participants. Road networks were not well developed and the roads leading to the communities were rough, muddy and very dusty particularly during the rainy seasons and harmattan (a cold-dry and dusty trade wind blowing over West Africa sub-region between the end of November and middle of March each year) respectively.

### Excerpt 1 from reflective dairy

I gained access to the community during my first research. I had a network with the community health nurses in the community. I telephoned one of the Community Health Nurses to find out if she had identified any potential participant for me. She then informed me that, the special teacher in the district had identified some children with cerebral palsy in his neighbourhood. I was worried about how the special teacher was going to introduce me to the caregivers, which might influence the responses I will be receiving. On the other hand I did not want to tell him what to say. One reason was because he was a man and also older than me (in the Ghanaian society women are expected to respect men and the elderly). Upon meeting the Special teacher, I emphasised the fact that I was a research student combining my research towards my PhD and working as a lecturer at the University. I felt that if I was perceived as a partner to the NGO, or an expert, the people will see me as someone who was going to provide solutions to their problems either financially or medically and might exaggerate their experiences. I monitored this by doing a comprehensive introduction of myself to the caregiver to counteract any adverse introduction made by the special teacher. I then arranged with the special teacher to see the caregivers of the children identified.

During our visit to the first caregiver, I expressed my intension to recruit her for my study, which she agreed; I then read and translated the information sheet to her. She readily accepted my request. I asked for the time that I can come and conduct the interview. To my surprised she told me that she was ready that very moment only if I am also ready. Her worry was that I have travelled from the city to her village and it will be unfair for her to give me another time. She thumb printed the consent form. I then asked her if I can briefly ask few questions about her child. With reference to the guide for identifying children with disability by Werner (1999) and my clinical experience, all the signs indicated that the child was having cerebral palsy. After observing all protocols I started the interview.

I found that one of the most tiring aspects was not being able to provide privacy. I knew it was ethically wrong for a health professional to conduct emotional interviews in the presence of a third party. Privacy

was not ensured as the special teacher was present during the interview. I asked the woman first if the special teacher should excuse us, but she agreed for him to be around. In my opinion she was more familiar to him than me. My challenge is how to arrange the interviews such that I can ensure privacy. It was difficult to locate the houses if one is not familiar with the area. There are no house numbers, routes are not straight forward. I don't even think I can get the direction to the house if I have to be there another time. Thus a third party will always be around. I don't think our Ghanaian culture will permit the caregivers to ask the person who introduced me to them to be excused during the interview. After the interview I noted in my research journal that the mother was stealing glance at the teacher when I asked her where the husband was, and the support she had been receiving from her community. Why was she doing that? Maybe the Teacher personally knows the husband, or she was finding it difficult to discuss family issues with an outsider which was against their culture. My challenge is that I cannot locate the house and go there alone. **(Excepts from reflective dairy)**

After the initial interviews, I discussed with my supervisor and the recruitment procedure was amended. The CHNs arranged for me to meet the caregivers, who had expressed interest in being involved in the research, at their homes or in the CHNs office depending on the caregiver's choice. The main aim of the initial meeting was to establish trust and rapport with the participants. During these meetings I highlighted the purpose and the objectives of the study, reassured them of their anonymity and the confidentiality of the information they might give, explained the dissemination process, gave them opportunity to ask questions and gave them a participant information sheet (see Appendix II). I read, when potential participants were not able to read, and translated and interpreted (when necessary) the participant information sheet. The information sheet was given to them to

keep. I then arranged the interview date, venue, and time with the participants. I drew maps to direct me to the houses if the directions were complicated. The interviews were scheduled on average a week after the first meeting. This allowed the participants' time to reflect on the research, to prepare and to allow me to conduct the interview alone. On the day of interview, I set off early in the morning to go to the chosen venue. Three of the homes were located in very remote areas. This meant that I was only able to drive to a certain point and then I had to walk the rest of the way. The main strategies I used to safeguard my safety were to inform a colleague of my destination and travel plan and to travel when the road was busy with people going to farm and market.

#### **3.4.2.1 Participants recruitment details**

This section presents participants recruitment details to provide a bigger picture and understanding of the recruitment procedure. Due to the complex nature of the phenomenon being studied, the recruitment of each participant varied and it provided a unique contribution for identification of human resources that could be used in future research and planning of rehabilitation programmes.

Kofi was introduced to the study through the Assembly man in his community. Assembly men and women duties in Ghana among others is to raise funds, "monitor the execution of projects under approved developmental plans and assess and evaluate their impact on the people's development, the local, district and national economy (Ghana local government act 462 (1993)). The Assembly man was a personal friend to the special education specialist. The initial introduction of the study to Kofi was done by the special education specialist. Kofi lives in a rural community where there is no electricity or water

supply, no schools, no CHPs compound to deliver health services. The community members have to depend on the facilities in a nearby community which was about 15 minutes' drive. On the day scheduled to meet the Kofi, I had to travel for an hour to pick the special education specialist from his office, then to the assemblyman who finally sent us to meet the potential participant. Kofi lives in a big compound with two semidetached houses built with earth based bricks. Kofi was the head of his household. He lives with his wife, five children, his cousin with cerebral palsy and two other siblings Kofi mentioned that he is the primary caregiver. After the first meeting Kofi opted to meet me at the District Health Directorate office building. The interview was conducted in the conference room.

Afua was recruited into the study through the special education specialist. The younger sister of the child with cerebral palsy mentioned her sister's condition to her class teacher and the teacher then informs the special education teacher. The educationist did the initial contact arrangement. Both meetings with Afua took place in her house. She lives with her mother, sister and two of her children.

Kwaku was introduced into the study through a friend and through the Community Health Nurse. Kwaku's friend got to know about the study through the flyers distributed by the community health nurses. Kwaku's house was located near Capital Township of the district. I personally contacted Kwaku and was directed to his house. The first meeting and the interview took place in his house. Kwaku lives in the house with his three other siblings and their families, and two other tenants who were not close relatives.



The community health nurses introduced Akua, Esi and Abena to me. The recruitment of these three participants was simple as they sent their children to the community child welfare clinic. Furthermore they agreed that the interviews should take place at the CHPS compound after going through the clinic protocols.

Awo, Nana, Mena and Eno, were recruited into the study through the community health nurses after distributing the flyers. The intervening process of the four participants were smooth except the houses were far and the road network was bad.

Adwoa was informed about the study from the wife of the chief of her community who received one of the flyers from the community health nurses. Locating Adwoa's House was very complicated. Adwoa directed me to the house. She met me at the town centre and took me to her house, to my surprise, we drove for about 15 minutes, then I had to park my car and we walked for another 20 minutes. Adwoa lives in an isolated house near the farm lands with her children. The house was a single room with no toilet and bath or kitchen. She had constructed a small bathing area where she had screened with old aluminium sheets. I was surprised why she was living in that isolated place. Adwoa's had to leave her work because of negative attitude from the society. Adwoa interview was done the same day meeting her. Adwoa has to walk anytime she wants to come to the township to do shopping. The isolated nature of her house was revealed in her narratives, she said "Yes at times I do cry and ask God why all this is happening to me, sometimes I tell God that he should allow me to be able to mingle with people". The interview lasted for an hour and half.

## Excerpt 2 from reflective diary

I couldn't control my emotions when I got back into my car. I shed tears while I was writing my reflections in my dairy. My initial reaction to Adwoa condition was to reflect and ask what might be wrong. Is it ignorance, which has led to the irresponsibility on the part of the leaders of our community? Why did the Chief wife waited till this study before seeking for help for Adwoa. I don't blame anyone; I blame the government and the system.

I always blame the system and government because of my experience in the developed countries. In developed countries the systems work and there is social support and care for all. In our system there is absolutely no support for people who are not working. Some mothers may not be working because they have given birth to so many children, and others also have to care for a child who is sick or challenged.

On the other hand I get very upset and furious if the men, the fathers and husbands abandon and neglect them. I later break down because there is nothing that can be done to such men. There are laws but they are poorly implemented as compared to the developed countries. Adwoa looks depressed and hungry. Immediate action should be taken as Adwoa condition could result

in her getting depression or attempting suicide as she even mentioned it in the interview. Adwoa looks very tired as she carried her child with cerebral palsy at her back and walking for this distance. I gave her money on the day of interview and introduced her to the community outreach program. Upon discussion with the Chiefs wife we had a meeting with Adwoa and we encouraged her. I couldn't end the relationship with Adwoa after the research activity. Adwoa was scheduled for an ongoing support from CBM (Excerpts from reflective diary).

The special education teacher introduced the study to Akosua. I went to Akosua's house for the first time with the educationist. The house was not far from the community centre. Akosua lives in the house with the brother and the wife with two children. The house was a two semidetached chamber and a hall. The area for cooking was outside under a hut. There were no toilet in the house and they had to use the public facility for a fee. Akosua was unemployed because of her son's condition. On the day of interview I went to the house alone. I experienced some resistance in getting information from Akosua. Akosua looks irritated and angry. Hence the introduction stage of the interview lasted for about 15 minutes because I had to try and establish rapport.

In summary the recruitment process was successful as all the participants contacted gave their consent to take part in the study. Community health nurses, special education specialist, an assembly man, and a chief wife were the human resource used for the recruitment of participants.

### **3.4.3 Sample size**

Rubinstein (1994) opined that there are no hard and fast rules about sample size in qualitative research and, according to Englander (2012), the question about the number of participants is irrelevant once the decision has been made to conduct a qualitative study in contrast to the sample size issues characteristic of quantitative studies. Kvale (1995) affirms that in qualitative research the number of participants involved depends on the degree and richness of the information they are able to provide, and it is this that informs the sample size decision. A review of guidelines for determining sample size in qualitative studies revealed that the majority of qualitative study sample size decisions were informed by the concept of data saturation (Mason, 2010; Charmaz, 2006; Ritchie et al., 2013).

Data saturation refers to the stage in the data collection process when new data does not yield any further new information or no new themes or patterns related to the phenomenon being studied appear to be emerging (Mason, 2010; Guest, Bunce and Johnson, 2006). Morse (1995:147) simply defines it as “data adequacy”. According to Guest, Bunce and Johnson (2006:60), the concept of data saturation has become the “gold standard by which purposive sample sizes are determined in health sciences research”. Meanwhile some controversy has developed about the subject of data saturation, in

particular, whether it can be achieved or not. Although, Bowen (2008) suggested that there should be a detailed description of the evidence for data saturation and how it is achieved, many researchers claim to have reached data saturation but are not able to prove or justify it (Morse et al., 2008). Mason (2010) is of the view that the round figures or multiples of five figures that most qualitative researchers quote as their sample size suggest an insufficient grounding in data saturation. Mason (2010) concluded in his systematic review of sample size and saturation in PhD studies using qualitative interviews, that the studies did not show any clear indication of adhering to the guidelines of saturation. Furthermore, Mason (2010) deduced that PhD researchers do not really understand the concept of saturation and are doing comparatively large number of interviews with the intention of making their studies defensible. Interestingly, Guest, Bunce and Johnson (2006) conducted a study to answer the question “how many interviews are enough” using data from sixty in-depth interviews conducted in Ghana and Nigeria, with explicit purpose of investigating the number of interviews that would provide data saturation. They conducted their analyses in sets of six interviews and finally posited that data saturation had occurred by the time they had analysed twelve interviews. Hence they strongly argued that six to twelve interviews would be enough if purposive samples are carefully selected and the participants are chosen according to some defined common criteria. Morse (1995) also posited that the *quantity* of data does not reflect saturation; it is the *richness* of the data that informs the detailed description of the phenomenon being studied that is important.

As a novice in qualitative research, I was keen to know the exact guidelines for achieving the correct sample size for qualitative research and the issues concerning data saturation. However, it became clear that there is no consensus or evidence to support specific sample sizes or how many interviews is enough. According to Baker and Edwards (2012), both novice and experienced established qualitative researchers are required to provide concrete sample sizes for the purposes of writing research proposals and research grant proposal and ethics submissions. However, 14 renowned social scientists and 5 early career researchers, when asked the question ‘how many,’ simply responded “it depends” (Baker and Edwards, 2012). The sample size decision in qualitative research depends on the philosophical foundations of the study, particularly the epistemological and methodological questions asked, as well as whether it is appropriately practical (Guest, Bunce and Johnson, 2006; Baker and Edwards, 2012). Many authorities in descriptive phenomenological studies recommend that researchers recruit at least three participants (Giorgi, 2009; Kvale and Brinkmann, 2009; Englander, 2012). According to Englander (2012:21), in conducting descriptive phenomenology: “one seeks knowledge of the content of the experience, often in depth, to seek the meaning of a phenomenon, not “how many” people who experienced such phenomenon”. For the purpose of this study the initial sample size decision was pragmatic i.e. to interview as many caregivers as I was able to identify and who were eligible to be recruited for the study within the time frame set for the data collection. However, achieving saturation was compromised by the complexity of the phenomenon being studied and the practical issues involve. A total of twelve participants were recruited for this study over a period of six months. I was satisfied with the depth of all the interviews conducted. Although I did not interview more people until

achieving data saturation, after the tenth interview similar accounts were given by the caregivers.

#### **3.4.4 Data Collection Procedure**

The most commonly used methods of qualitative data collection are participant observation, individual interviews, and focus group discussion (Ulin, Robinson and Tolley, 2012). Qualitative interviews are usually defined as unstructured or semi-structured (DiCicco-Bloom and Crabtree, 2006; Crabtree and Miller, 1999). An unstructured interview, commonly used in ethnographic studies, is more or less an unguided conversation and it is usually used in conjunction with participant observation and field notes. Semi-structured (or in-depth) interview is the most common method used in phenomenological studies (DiCicco-Bloom and Crabtree, 2006). According to Horton, Macve, and Struyven (2004: p. 340): “semi-structured interviews are chosen in order to allow the interviewees a degree of freedom to explain their thoughts and to highlight areas of expertise that they felt they had”. Furthermore, Campbell and Scott (2011) suggest that semi-structured interviews facilitate exploration of the richness of lived experiences from the perspectives of those who have direct involvement with the phenomenon of interest.

In-depth interviews were selected as the primary data collection method for this study with the intention of generating rich and detailed data on the phenomenon being studied. The data collection procedure of this study conformed to the context of Husserlian descriptive phenomenology (Giorgi and Giorgi, 2003). Therefore semi-structured interviews were used as a means of exploring and gathering experiential narrative material

that may serve as a resource for developing a richer and deeper understanding of the phenomenon being studied (Van Manen, 1990).

Recently, focus group discussion has been introduced in conjunction with phenomenological studies despite considerable criticism about its compatibility (Webb and Kevern 2001). Bradbury-Jones and Sambrook (2009) strongly advocate for the use of focus group discussion in phenomenological studies considering that the group dynamics could stimulate discussion and open up new perspectives. In addition, they are optimistic that individual experiences could be preserved within the group context if each participant is given the chance to share their experiences. In contrast, Sharma (2005) envisages a potential threat to openness especially on sensitive topics and that “people might not speak what they think but what someone else wants to hear” (p.42). Upon critical reflection, individual (in-depth) interview was chosen for the purposes of this study notwithstanding the advantages of focus group discussion being inexpensive and a relatively quick means of collecting data. Another consideration in making this decision was primarily ethical and concerned with the confidentiality of the individual experiences that would be shared. According to Gibbs (1997) participants need to be encouraged to keep confidential what they hear during the focus group discussion. In view of the level of vulnerability of the participants in this study, ethical considerations were of priority and I felt that there was no room for compromise. Furthermore, Sharma (2009) recommends that to ensure that discussion is more honest, efforts need to be made, such that participants do not know each other (p.42). This recommendation could not have been applied in this study as some of the participants were recruited through the snowball approach, and would have known each



other. In addition, I was not convinced by the argument made for use of focus groups in phenomenological research. Phenomenology focuses on understanding individual experiences and abstracting these to develop the 'essence' of the phenomenon being studied and, therefore, in-depth interviews were chosen as the most appropriate method of data collection.

Englander (2012: 34) suggested that: "critical phenomenological reflection on a previous interview makes the researcher a more present and skilled interviewer". As a physiotherapist, my broad knowledge of cerebral palsy and its consequences, meant that I had a tendency, particularly initially, to direct the interview such that the emerging issues would fit into an appropriate medical category in order to choose appropriate interventions similar to a clinical interview (Britten, 1995). These issues of influence and the researcher role are discussed in depth in Chapter 5 which focuses on the reflexivity issues inherent in this study. Britten (1995: 252) commented that: "in a qualitative research interview the aim is to discover the interviewee's own framework of meanings and the research task is to avoid imposing the researcher's structures and assumptions as far as possible". Hence two pilot interviews were conducted before the main data collection began.

The purpose of conducting the pilot interviews was to give me the opportunity to become familiar with the interview process (use of digital recorder, establishing rapport etc), to develop relevant lines of questions and qualitative interviewing skills and make any modifications to the interview guide (Carpenter, 1997). The two participants selected for the pilot interviews were mothers of children with cerebral palsy living in the community that I had made contact with in a previous study, and who volunteered to be interviewed.

These two participants were mothers of children with cerebral palsy who had not received any form of therapy. It was my prior connection with these mothers that, in part, had motivated me to plan and implement this study. After the pilot interviews the mothers were asked to critique the questions asked and suggest more or alternative questions. The pilot interviews were transcribed verbatim, translated to English and back translated to Twi by me immediately after the respective interviews. The Twi version of the interviews were read to the participants and they were asked to suggest any further questions that could have been asked to establish a context and fully explore the topic of interest. The participants of the pilot study suggested that the questions should be short; otherwise it will confuse the interviewee.

A revised interview guide was developed incorporating the suggested questions, and issues identified during my reflection on the pilot interview process and the field notes. The pilot interview transcripts were shared with the supervisory team and my pilot interview experience discussed. The supervisory team members have considerable experience in qualitative interviewing and the discussion contributed to my conducting a third pilot interview and a second interview with one of the participants with the aim of her confirming the improved quality of the interviewing guide. Furthermore the supervisory team conducted a bracketing interview with me and guided my reflection of this experience in order to assist me to make explicit the assumptions, beliefs and values I had about topics related to the study e.g. living with a disability, the importance of rehabilitation, my definition of caring. These will be discussed in more depth in section 3.6.4.1

Before each interview I again informed the participants about the purpose and objectives of the study, assured them of confidentiality, and reviewed what was required of their participation. After answering any questions that they had, I asked the participants to sign or thumbprint the consent form (see Appendix III). Interviews were conducted as a single face-to-face in-depth interview in a quiet venue, chosen by the participant, for example in their homes, at the CHPS compound or in a church building (most health screenings that require optimal privacy for the community members are normally done in church buildings out of church hours). Single in-depth interviews were conducted because, as Haahr, Norlyk and Hall (2014) suggested repeated interviews may cause blurred boundaries between doing research and caring for the participants i.e. the researcher and clinician roles. As a physiotherapist, I have knowledge of the consequences of cerebral palsy and the variety of interventions available. Subsequently there was a tendency for me to provide health education during the interview. A conscious effort was made to bracket my desire to assume the clinical role and my professional practice experience instead served as a valuable tool to identify significant issues arising from the interview and to effectively ask probing questions.

Patton (1990: 348) considers audio recording during qualitative interviews as being “indispensable”. Audio recording helps the interviewer to be more focused on the interview as opposed to note taking. Participants were informed that interviews would be audiotaped and their permission was obtained, and the operation of the tape recorder was demonstrated to them as none of the participants had seen one before. I used a Sony digital audio recorder to record all the interviews. The participants were also informed that they

could ask for the tape recorder to be turned off at any time if they wished. Hence all interviews were audio recorded with the participants' consent. The interviews lasted between 90 to 120 minutes.

The interviews were conducted in the participant's preferred language. The first few minutes of each interview focused on soliciting demographic data from the participants. The intention was to give the participants confidence and motivation in responding to questions that were familiar and easy to answer. They were asked to explain their relationship, when they started caring for the child and how they got to know that the child had cerebral palsy. Then the interview continued using a guide of broad questions (see Appendix IV) and additional probing questions were asked to explore the broad topics in more depth. After the interview the participants were asked whether they had anything to add or any questions to ask. The audio recording was stopped when participants indicated that they had finished. The participants were also given the opportunity to add any information after the recorder was turned off. The interview always ended by me thanking the participants. Field notes were written 60 minutes after the interview, usually when I was back in the car. The content of the field notes included the location of the interview, a description of the environment, non-verbal behaviour observed, technical issues, and the gist of the ad hoc conversations that occurred with the participants before and after the interview when the digital recorder had been turned off, and anything that was observed or occurred before, during or after the interview. Field notes were labelled with the interview number. The field notes, in addition to the interview, helped the researcher to capture the unique details about each interviewee's situation. The tapes were

transcribed verbatim within 48 hours to ensure maximum recall of all the necessary issues that occurred during each interview session. A detailed description of the transcribing and translating process is presented below in the data analysis section 3.7.1.

### **3.4.5. Ethical Considerations**

According to Orb, Eisenhauer and Wynaden (2001), ethical issues in qualitative research are sometimes not apparent and not addressed by researchers, but protection of participants in any study is paramount and is the responsibility of the researcher. Qualitative researchers encounter ethical dilemmas throughout the research process (Pesonen et al., 2011). The ethical considerations in conducting phenomenological research are particularly important as the researcher relies heavily on the subjective experience of the participants and consequently, on the relationship that can be established between the researcher and participant. The ethical principles associated with other phenomenological studies (Pesonen et al., 2011; Smith, 2008; Mcfatrik, Sullivan and McKenna, 2005; Orb, Eisenhauer and Wynaden, 2001) were used to guide this study in relation to the ethical principles of beneficence, non-maleficence, respect for the autonomy of the participants, and the Declaration of Helsinki (World Medical Association, 2001).

#### **3.4.5.1 Principle of beneficence**

The principle of beneficence is an obligation to help others to achieve the interests that are important and legitimate to them (Beauchamp and Childress, 2001). This principle requires that the researcher reflect on participants' needs and feelings as well as ensure that their involvement in the research and relationship with the researcher is of benefit to them (Mcfatrik, Sullivan and McKenna, 2005). The principle of beneficence underpins the

sharing of information with participants throughout the research process but in this study it was primarily applied after reflection on the pilot interviews. After the pilot interviews, it was clear that the participants' expected me, as the researcher, to assist them to find solutions for their children with cerebral palsy. This expectation became a considerable burden and I felt a responsibility to put in place some assistance for these children who are not receiving any care. As a result, with the aid of CBM international, Non-Governmental Organization (NGO) a community-based parent training programme for parents and caregivers of children with cerebral palsy was established. A physiotherapist was paid by the NGO to provide training for caregivers on a monthly basis. The sustainability plans for this programme are on going. This training provides the designated caregiver of the child with basic skills related to safe handling techniques and positioning to facilitate motor development. All the study participants chose to be recruited into the training programme after their respective interviews. Caution was taken that participation in this study was not perceived as a requirement or prerequisite for being offered the training program. The participants were informed that their recruitment into the caregiver-training program did not depend on their participation in the research and vice versa.

#### **3.4.5.2 Principle of non-maleficence**

McIlfatrick, Sullivan and McKenna (2005:42) highlight the potential harm that an in-depth interview might cause for the participants as opposed to the potential benefit to them of giving them the opportunity of reflecting on, and gaining a deeper understanding of, their experience and they recommend establishing a balance between such risks and benefits. The principle of non-maleficence encompasses the freedom from both physical and

psychological harm (McIlpatrick, Sullivan and McKenna, 2005). According to Dickson-Swift et al. (2006) interviews that focus on sensitive issues and the private lives of individuals can cause emotional distress to both the participants and the researcher. The major challenges are establishing boundaries about the type and nature of the questions to be asked and the relationship between the participants and the researcher (Haahr, Norlyk, Hall, 2014). In this study, I maintained the researcher role as much as possible and I realized that any attempt I made to detach myself (be more objective) during the interviews created additional stress for the participants to that associated with being involved in research. I consistently made every effort to bracket the feelings of being a friend, a therapist, a counsellor and the professional obligation to provide assistance in order to authentically listen to what the participants were telling me. To counteract potential role conflict I ensured that the participants were clear about my role and purpose in conducting the interview and that I was not in the position to provide therapy. Furthermore I was determined to manage the emotional burden by keeping a reflexive research diary and sharing my experiences with the supervisory team as recommended by Pesonen et al. (2011). In addition, I followed the guidelines for protecting participants' emotional responses recommended by McIlpatrick, Sullivan and McKenna (2005:42). These authors suggest that at the end of the interview "the researcher should thank the participants for being so open and honest; highlight the fact that the various issues raised within the interviews were important and perhaps they would need to discuss these with other people; rendering appropriate support and arranging appropriate referrals". After some of the interviews, caregivers expressed their appreciation for talking to them. For example one

care giver said “I feel very okay talking to you. I can see that you understand me. It means you care and understand my problem. No one seems to understand me” (Akua).

#### **3.4.5.3 The principle of respect for autonomy**

Respect for the autonomy of participants “refers to each individual’s right to hold views, make choices and take actions based on personal values and beliefs” (Haahr, Norlyk and Hall, 2014: p. 10). This principle recommends that researchers should provide information about the study and ensure that participants’ understand the information and that their participation in the research is based on voluntariness and understanding (Haahr, Norlyk, Hall, 2014). In addition, potential risks and benefits associated with participants’ involvement in the study were thoroughly discussed. All participants gave their permission for anonymized verbatim quotations to be published. To ensure anonymity, pseudonyms and codes were assigned for each participant in transcripts, study-write up and in disseminating the results.

Ethical approval for this study was obtained from the Ghana Health Service Ethical Review Committee and the Coventry University Research Ethics Committee before commencement of the study (see Appendix VII ).

### **3.5 Strategies used to ensure the rigour of the study**

Several strategies were incorporated in the study design with the intention of ensuring the quality of the study. Merely stating the aim of the research and the methodological approach taken does not guarantee the rigour of the research process and how it is reported (Hammell and Carpenter, 2004). The evaluative criterion of credibility focuses on the degree to which the study findings accurately represent the participants’



multiple realities. This was maintained by being consistently reflective during the research process particularly the data collection and analytic phases (Shenton, 2004; Speziale, Streubert and Carpenter, 2011). Throughout the study design and implementation I kept a reflexive diary in which my assumptions, thoughts and ideas about the research topic and what the participants revealed during the interviews were noted. Reflexivity (discussed in greater detail in the subsequent section) was addressed in order to make explicit how I, as the researcher, potentially or in reality, influenced the study process. My experiences in rehabilitation of children with cerebral palsy were bracketed in an attempt to reduce the influence I had on the participants' expression of their unique experiences.

Peer review was carried out at various stages of the research process by the doctoral supervisory team, particularly the Director of Studies, who has experience in qualitative research and the topic being studied. In addition, member checking was used for the purpose of ensuring that the participants' experiences were accurately represented in the data. Member checking or member validation is the process in which participants are asked to review their transcribed interviews and/or the data analysis process, and provide feedback on whether the content was accurately recorded and the abstracted data i.e. the main themes generated are meaningful to them (Lincoln and Guba, 1985; McDonnell et al., 2000; Houghton et al., 2013). The process empowers the participants to contribute in a meaningful way to the research process. Lincoln and Lincoln and Guba (1985) described member checking as a "conspirational agreement;" a consensus between the researcher and the participants on the content of the transcribed interviews and how it was ultimately interpreted. A review of the literature revealed that there is a paucity of information or guidance about how to conduct member checking. Two main methods,

individual and group member checking, were identified in the studies reviewed. In the individual method the transcribed interviews or summaries of themes were given to individual participants to either merely confirm the interview content or to provide feedback on the overall themes generated from the interviews (Doyle, 2007; Rodger and Mandich, 2005; Ann et al 1999). In the second method a group of participants are given a summary of the results, that is, the themes for validation and confirmation are discussed in a group session (Klinger, 2005; Nagle et al., 2002; Buck et al., 2004). The member checking process adopted in this study was discussed extensively with the Director of Studies. Detailed description of the procedure is presented in the step seven of the data analysis session 3.7. Finally a comprehensive description of how the study was conducted and an honest discussion of any issues that occurred during the course of the research i.e. a decision or audit trail is provided.

### **3.6 Reflexivity**

Reflexivity is the analytic attention to the researcher's role in qualitative research and addresses the process by which researchers identify their position and influence throughout the research process (Dowling, 2006; Savin-Baden and Major, 2013, p: 76; Primeau, 2003). One of the characteristics of qualitative research is the integrated and interpretive role of the researcher. Moreover, in qualitative research, "researchers both influence and are influenced by the process of engaging in the research" (Northway, 2000: p. 392) thus the relationship established between the researcher and the researched is acknowledged.

Koch and Harrington (1998: p. 882) contended that “researchers bring to the research product, data generated, a range of literature, a positioning of this literature, a positioning of oneself, and moral socio-political context”. Therefore as part of my reflexive process, the bulk of the literature review was conducted after the data analysis. It is also recommended that the researcher should acknowledge the co-construction of knowledge role and declare the multiple levels that they are involved in the research process and results (Etherington, 2004; Horsburgh, 2003). Such a declaration will “enhance the trustworthiness, transparency, and accountability of their research” (Finlay, 2002 p. 211). The issues associated with the role of co-constructer of knowledge made reflexivity an important and defining feature in this study (Seale, 1999, Banister et al, 2011). Therefore this section presents the concept and types of reflexivity discussed in the literature, the approaches used to achieve reflexivity, and how reflexive bracketing associated with phenomenological methodology was used in this study.

### **3.6.1 Concept of reflexivity**

*The pot carries its maker's thoughts, feelings, and spirit. To overlook this fact is to miss a crucial truth, whether in clay story or science (Susan Krieger, 1991, p.89 as quoted by Finlay, 2002b, p. 531)*

The concept of reflexivity can be traced to the late 1930's when qualitative researchers began to deliberate on the validity and quality of their studies and the relationship with self-consciousness (Primeau, 2003). The biographical characteristics of the researcher, such as, age, gender, ethnicity, employment, values, social and educational

status began to be acknowledged as informing their role and essential subjectivity (Dowling, 2006). Reflexivity positions the researcher in such a way that they can come to terms not only with the choice of problem or relationship with participants, but also with the concepts of multiple realities and relativist knowledge co-construction (Denzin and Lincoln, 2005). These identities or new understandings of the researcher role were described by Reinharz (1997) as ‘selves’ that can influence the study that originate from three main sources; research based, brought selves (that comprise the individual’s historical, social and personal views) and situational selves which are created in the course of the research. Reflexivity also questions the basis of the researchers’ assumptions (Northway, 2000). Reflexivity can be defined, somewhat simplistically as, an essential strategy that “enhances the quality of research by making explicit the deep seated views and judgements that affect the research topic, including a full assessment of the influence of a researcher’s background, perceptions and interests on the research process” (Carpenter & Suto, 2008, p. 125).

The process of comprehending the difference between supposition, biases and subjective interpretation and the need to make explicit deep seated views has caused many authors to perceive the concept of reflexivity to be complex, ambiguous and unachievable (Carpenter and Suto, 2008; Finlay, 2002). Furthermore, the existence of, as Creswell (1998) says, “a baffling number of [methodological] traditions from which to choose (p.4) have resulted in “competing, sometimes contradictory, accounts of the rationale and practice of reflexivity” (Finlay, 2002b: p. 533). As Dowling (2006, p.8) opined: “achieving reflexivity is not a straight forward endeavour”. The difficulties of achieving reflexivity

and the danger of the concept being used simply as a strategy by which the academic rigour of the research could be assessed, has been identified (Allen, 2004). According to Finlay (2002, p.212) “qualitative researchers no longer question the need for reflexivity: the question is how to do it”. Hence qualitative researchers have identified several types and approaches of reflexivity in an attempt to give analytical attention to the researcher role (Dowling, 2006).

### **3.6.2 Types of reflexivity**

Personal reflexivity, also known as ‘self-awareness’ (Giddens, 1977 as quoted in Dowling, 2006: p. 8), accounts for much of the discussion in qualitative research texts that reflect the researcher interest, experiences, beliefs and personal positions (Savin-Baden and Major, 2013). Qualitative researchers should be able to articulate who they are and what they believe so that they can appreciate the possible ways they can influence the study. The idea of self-reflexivity encompasses the action of a researcher to engage in self-examination, self-awareness and self-critique in order to discover salient assumptions, intuitions and biases that could influence the phenomenon being studied, and these should be made explicit in the research report (Northway, 2000; Ahern, 1999).

Reflexivity from a critical standpoint or ‘politics of location’ is another form that has been discussed in literature (Dowling, 2006; Northway 2000). Koch and Harrington (1998) affirm that the principle of analysing the social and political structures that inform the research process is a major constituent of reflexivity and Hands (2003) emphasised the relevance of analysing the political environmental context of research. Finlay (2000b)

suggests that tension or power imbalances can arise due to differences in social position and are informed by issues of gender, race and/or social class between the researcher and the researched. Hence reflexivity as a social critique will expose and address power imbalances in the research process. Some authors (Oliver 1992, Zarb, 1997) recommend that the political and social constructions, relating to the phenomenon being studied, should be identified, critically analysed and changed in order to empower participants contributing to research. To achieve this reciprocity or reciprocal sharing of knowing should be promoted (Northway, 2000; Dowling, 2006). Reciprocity supports a genuine relationship between researcher and participants, for example, researchers sharing personal information with participants (Vernon, 1997) and disclosing their values and beliefs during the research process (Northway, 2000). Whitehead (2004) cautioned that health professionals' attempting to promote reciprocity should avoid creating a therapeutic relationship where participants ask questions pertaining to their illness. According to Muecke (1994) reflexivity as social critique is a component of ethnographic studies as the researcher's role requires immersion in the participant's context. Researchers conducting emancipatory disability research are also recommended: "to examine their own research practice and work towards transforming the social and material relations within the research process" (Northway, 2000: p. 394).

### **3.6.3 Achieving reflexivity**

A number of strategies to promote reflexivity have been highlighted to assist researchers in articulating their personal suppositions in a meaningful way and in accordance to the phenomenon being studied and the research process (Dowling, 2006;

Rolls and Relf, 2004; Savin-Baden and Major, 2013; Northway 2000). One such strategy is the need for the researcher to go beyond private contemplation and assume the position of being an 'object' (Dowling, 2006; Aron, 2000). An example of this strategy was described by Rolls and Relf (2004): the researcher engaged in series of interviews with the supervisory team in order to assist her to identify her assumptions and past experiences that might influence the research. Richardson (1997) argues that reflexivity can be successfully achieved if the one interviewing the researcher is a peer or supervisor who can challenge the researcher's self-deceptions. These self-deceptions are the assumptions and motivations that remain hidden from the researcher even after he or she had assumed a reflexive stance (Northway, 2000; Richardson, 1997). In contrast, Soltis-Jarrett (1997) used a form of reflexive dialogue between the researcher and the participants in which she periodically checked their understanding of the interview process against her own. This process can help researchers to become more aware of possible areas of influence and make these more explicit. The provision of a vivid account of what is going on, both 'implicitly' and 'explicitly' in the research process, will serve to signpost for readers how the researcher is positioned within the study (Koch and Harrington, 1998; Northway, 2000). Hence readers will be able to judge the quality of the research process and honesty and transparency of the research process will be promoted.

The use of a reflective journal is one of the most commonly used strategies to promote reflexivity. Keeping a research diary (Coulon, 1995) or a reflective journal (Koch and Harrington, 1998) throughout the research process is a significant component of reflexivity-in-action. The research journal acts as a record, from the beginning of the study, of how the researcher developed the theoretical perspectives and philosophical

assumptions that inform the framework of the study, as well as the emotional reactions and intuitions that developed during the research process (Gilbert, 2001). Keeping track of emotional events and responses, personal opinions and reflections can be relevant particularly during the analysis stage because it can assist the researcher to recognise where and when undue influence has occurred (Lofland, 1971 as quoted in Arber, 2006).

Furthermore, another aspect of reflexivity, from a critical point of view, is the dynamics of inter-subjective reflections (Finlay, 2002; Seale, 1999). Inter-subjective reflection is a self-reflective consciousness of where 'self' is in relation to others and becomes both the aim and object of focus (Finlay, 2002: p. 216). In this process the researcher critically analyses the nature of the relationship established between the researcher and the participants and explicitly explores how the phenomenon is conceptualised and acted upon which enhances the mutual inter-subjective creation of data (Im and Chee, 2003).

#### **3.6.3.1 Achieving reflexivity in this study**

Finlay (2002b) recommended that reflexivity should be started from the conception of the research where the researcher will reflect on the topic and his or her relationship with the topic and should be continued throughout the entire research process. With reference to this study, I wrote in my reflexive dairy extensive notes on the assumptions and preconceptions I held about caring for a child with cerebral palsy, how these were acquired through my interactions with caregivers in my clinical practice as a physiotherapist, and I tried to analyse how these had influenced each stage of the study. For an example I experienced the challenge of ensuring privacy during my first interview. I



reflected on the scenario and wrote it in my dairy with the intension to ensure privacy next time by not conducting the interviews the same day.

Savin-Baden and Major (2013) suggest that: “reality is subjectively and mentally constructed by individuals and groups” (p.56) hence it is assumed that the participants of this study – caregivers of children with disabilities - constructed the meaning they attributed to the phenomenon of caring for a child with cerebral palsy in their own unique world and the meanings were influenced by numerous contextual factors. Multiple realities or meanings were revealed because the participants’ contexts and specific social structures that shape their lives are different even though they may be occupying the same geographical area (Blaikie, 2007, Carpenter and Suto, 2008). Reality and the individual are not separate entities; therefore gaining an in-depth understanding of each individual’s perspective enabled the nature of their realities to be unveiled. I believed that the participants’ life-worlds were informed by how the world appears to them and the meanings they assigned to their experiences of the phenomenon. The results of this study represent the understanding and the meanings caregivers’ attributed to their experiences and I made every effort to ensure that these were truly presented without trying to interpret or predict the findings.

As the researcher, I wanted to attain a high level of disclosure of my beliefs and core values and the priorities derived from my education, upbringing, culture and occupation so that my position within the research would be clearly stated and I could ensure the trustworthiness of the study for the readers. According to Turner (2008) individuals may develop multiple identities derived from the diverse groups they belong to.

These multiple identities co-exist simultaneously and inform the individual's self-conceptualization. Furthermore, depending on the context, one of the multiple identities may become more salient. With regards to this study my professional identity was revealed as the most significant followed by my ethnicity and lastly gender.

I am both an academician and a clinician in the field of physiotherapy. My professional identity attained through professional socialization and acculturation had a significant influence on the study. The knowledge, skills, sense of occupational identity, values and norms of the profession I have acquired throughout the years have shaped my behaviour and self-conception (Adams et al., 2006). Nicholls (2010: p 497) opined that: "the human body is, in many ways, central to the physiotherapy profession's identity because it is the site upon which much of our therapeutic work takes place". Hence my knowledge and expertise focuses on managing health problems that relate to the function and dysfunction of the body as well as the rehabilitation of children with disability. I am of the opinion that the health systems in Ghana, where I am currently practicing, are inefficient; there is a severe shortage of health professionals and deficiencies in service delivery complicated by many misconceptions about childhood disability. As a result, the majority of children with cerebral palsy in the rural and suburban communities do not receive any form of rehabilitation. This issue became evident in previous research we conducted (Nyante, Baltussen and Asante, 2012) and in Tinney et al's (2007) study where their conclusion was that there is virtually no medical rehabilitation for person's living with any form of disability in Ghana. This previous research motivated me to embark on this study.

As mentioned earlier, my professional interest and knowledge of cerebral palsy and how it affects childhood development had an influence on the interviewing process. During the interviews there was no need for the participant to explain the physically disabling nature of cerebral palsy, which they may not have understood themselves. My expertise placed me in a better position to probe more into the meanings the caregivers attributed to their experience of caring for the child instead of being distracted by their explanations of the presenting signs. This conformed to Hammell, Carpenter and Dyck's (2000) perception, that "professional expertise and accumulated knowledge can be valuable tools in the data collection process of a qualitative research" (p. 31).

Physiotherapy had become a major contributor in physical rehabilitation. In developing new approaches to rehabilitation, the physiotherapist takes a holistic view of the presenting impairments that represent disability. According to Smart (2009): "models of disability define disability; determine which professions serve people with disabilities, and help shape the self-identities of those with disabilities" (p. 3). The social model of disability significantly influenced this study because the model provided a better understanding of the interplay of the social context and individual disability experience and it shaped the development of the research process.

The philosophical assumption of social model of disability is that individual choices are dictated primarily by the structure and ideology of the society (Oliver, 2009). The model argues that how disability is perceived and defined is the result of the way society is organised and by the shared understanding and attitudes of the members of the society and these are central to the construction of the experiences of the people with

disability and their families (Oliver, 2009). In this model people with disability view themselves as minority in the society that had been denied of their rights (Smart, 2009). People with disability and their families' experiences are impacted by multiple factors, such as, oppressive social attitudes like distrust, fear, hostility, pity and over protection coupled with lack of rehabilitation services and social support (Barton, 1996).

The social model of disability has also contributed to people with disability gaining their civil rights. In addition, the United Nations Convention on Human Rights of Children to Life (UN, 2000) states that "governments must do all they can to make sure that children survive and develop to their full potential". Hence this model and the UN's statement of the rights of children were the sources of motivation for this study. According to Smart (2009) when the laws and attitudes of the society change, the experience of individuals with disability will improve. In Ghana people with disability are confronted with architectural, transportation, and public accommodation that restrict them fully participating in socially identified roles. With respect to the Ghanaian society, the quality of life of both children with disability and their families would be improved if anti-discrimination laws and policies were implemented by the government, if appropriate social support services and comprehensive rehabilitation programs were provided as well as physical and environmental barriers removed.

The social model raised my awareness of the impact of the social context within which people with disability live. I became emotionally affected when I reflected on how the lack of certain basic amenities had affected the quality of life of individuals living with different types of disability including cerebral palsy. I became aware that as a

physiotherapist and academic I needed to be an advocate and to develop and implement appropriate rehabilitation services for children with disability. The model has provided me with the tools to challenge prejudice, discrimination and to work towards changing the public conceptualization of disability. I believe that children have the right to be given health care according to their unique health needs and I became increasingly aware that caregivers, in attempting to find solutions for their child's health needs, might engage in traditional practices that can harm their children and negatively affect their health. In turn, I realised that I needed to better understand the stresses the caregivers experience, how they gain the strength (social, emotional, spiritual and physical) to cope with their stress and the possible support they receive from their family, community members and the health care system.

The World Health Organisation's (WHO), International Classification of Functioning, Disability and Health (ICF) framework had further influenced this study. The ICF is a tool for classifying the consequences of injuries and disease, and considering personal and environmental factors, in order to focus on what is important to the individual (Davis, 2006). The ICF seeks to identify impairments, activity limitations and participation restrictions, which are, explained as perceived problems of body function and structure, difficulty in executing task and action, and problems in functioning at the societal level respectively (WHO, 2007). According to Davis, (2006) the philosophy of rehabilitation is about enabling, facilitating and empowering, and is represented by the ICF framework. The concept of the ICF highlights the need to take holistic view of an individual's situation and to tailor interventions so that they are relevant and beneficial for each individual. The

conceptual framework of ICF influenced my interest to explore the meaning and understanding that caregivers bring to the functioning, quality of life and participation of children with cerebral palsy. In addition to explore the personal and environmental factors of caregivers of children with cerebral palsy, with the assumption that these factors are important to inform the rehabilitation needs of their children.

I agreed with Goodman (1978), a constructivist philosopher, who said “world making as we know it always starts from world’s already on hand; the making is remaking” (p.6). The historical background of a society is relevant in understanding what the society endorses or supports (Hughes, Sharrock and Martin, 2003). Bellah (2006) opined that it is important to first consider the history of religion before you can really understand a society. Religious traditions created by a society are the symbolic representation of reality (Hughes, Sharrock and Martin, 2003). According to the historians, Ghanaians originally migrated from the ancient kingdom of Ghana, western Soudan in the area of Mauritania and Mali, which was a Muslim community.

“Modern Ghanaians are able to belong and utilize several disparate religious traditions without feeling major contradictions” (Addo, 1997, p. 9) because the original Ghanaians were a people deeply rooted in religion. Although the majority of Ghanaians have adopted either Christianity, Islam or traditional religion, they easily adapt to any of the religious traditions in order to get solutions to their problems, despite being primarily affiliated to one religion (Addo, 1997). Ghanaians’ perceptions about people living with disability and their search for medical services as well as other health interventions are influenced by their religious beliefs. Many Ghanaians perceive the cause of disability as a

natural cause, hereditary, a blessing or punishment from God, evil forces or other deities, and they seek for solutions in accordance to their belief. The religious beliefs have profound influences on parenting and caring for a child with disability. In other words, caregivers' realities and essence of the meaning they attribute to the role of caring would be influenced by the history and cultural beliefs passed from generation to generation.

Reflexivity has a different significance when discussed in relation to different qualitative methodologies. For example, in ethnographic research, researchers use reflexivity to portray the integrity and trustworthiness of their findings (Finlay, 2002). In feminist research, reflexivity tasks the researcher to identify their own taken for granted values and how these values influence judgements made in the study (Manias and Street, 2001). Phenomenologists, on the other hand, prefer the "voices of subjectivity to emerge authentically in coming to an understanding of what essentially the research respondents mean in their personal accounts expressed through the data collection devices" (Bednall, 2006, p.124).

Despite the significance of reflexivity in all qualitative research approaches, some challenges are associated with the expectation to be reflexive and qualitative researchers have elaborated these. Finlay (2002b) highlighted the dangers of overemphasising self-analysis at the expense of focusing on the phenomenon being studied. In avoiding this problem, Finlay (2002, p. 212) suggested that: "researchers have to negotiate the 'swamp' of interminable self-analysis and self-disclosure". In addition, engaging in reflexivity as self-analysis of one's own experience should not serve as the end but as a spring board from which to facilitate, describe, interpret and generate a more general insight and

understanding of the phenomenon being studied with respect to a particular context (Finlay, 2002b). From the phenomenologist point of view the conscious experiences of the participant are of critical importance. Therefore, bracketing is used, in association with descriptive phenomenology, as a further step in terms of addressing reflexivity issues.

### **3.6.4 Bracketing**

LeVasseur (2003) defined bracketing as a “reflective process by which opinion and prejudice are suspended to focus attention on what is essential in the phenomena” (p. 411). Bracketing is among the salient steps that characterise Husserl’s discussion of phenomenology and it was developed on the assumption that the object under study and the subject studying the object can be separated and, as such, can be viewed independently (Hamill and Sinclair, 2010; Byrne, 2010). “For Husserl, the aim of phenomenology is the rigorous and unbiased study of things as they appear in order to arrive at an essential understanding of human consciousness and experience (Valle et al., 1989 as quoted by Dowling, 2007: p. 132). This reflects Husserl’s desire to create a ‘scientific’ approach to exploring the ‘non-scientific’, that is, phenomenological methods can be used to attain objectivity and rigour, when researchers’ bracket or suspend all suppositions and biases (Koch and Harrington, 1998). Koch and Harrington (1998) affirmed that bracketing goes a step beyond reflexivity and it is used in Husserl’s approach to descriptive phenomenology to maintain the researcher’s neutrality or ‘objectivity’ within the research process. Phenomenological reduction or bracketing needs to be ensured before the conscious experiences of participants can be portrayed as being as free as possible from the researchers’ subjective perspectives and theoretical constructs, (Dowling, 2007). Hamill



and Sinclair (2010) opined that “by bracketing, the researcher does not influence the participants’ understanding of the phenomenon, thus it is their reality” (Hamill and Sinclair, 2010: p. 17).

There are diverse opinions about what stage in the research process researchers should bracket their suppositions. Drew (2004) considers that, as bracketing is a technique of holding one’s preconceived ideas and personal knowledge of the phenomenon, it is best done during the interviewing stage and when reflecting on the lived experiences of participants. Dowling (2006, p.10), on the other hand, views bracketing as the act of suspending all biases and beliefs regarding the phenomenon being researched and that it specifically depicts the validity of the data collection and analysis process, therefore, it is best done prior to data collection. In contrast, Arhen (1999) and Hamill and Sinclair (2010) consider bracketing as essential to the whole phenomenological study process. Since researchers’ subjective perspectives and theoretical constructs are integral to identifying the phenomenon to be studied and to articulating the research purpose bracketing should be promoted throughout the research process. In addition, Moran (2005) states that explanations are not to be imposed before the phenomena have been understood from within.

Secondly, there are diverse opinions about what is to be bracketed in phenomenological studies. The most common opinion is assumptions (Crotty 1996; LeVasseur, 2003), then judgement (Moran, 2005), and biases and beliefs (Dowling 2004). According to Beech (1999) researchers are recommended to bracket their experiences, knowledge, issues, preconceptions, biases and presuppositions. In my opinion, this means that bracketing focuses on whatever appears conscious and relates to the phenomenon

being studied. Caelli (2000) suggests that phenomenological researchers are very conscious of the effect that culture and societal traditions might have on the 'authentic' study of phenomena. In conducting this study I had to identify my personal suppositions and ideas about caring for a child with cerebral palsy so that I can make a conscious effort to minimize how these would impact on the development of the research question, choice of methodology and study design and implementation decisions.

Discussion with my supervisors made it clear that bracketing is not an attempt to be objective but rather an attempt to encourage researchers to set aside, as much as possible, their internal beliefs, experiences, understandings, biases, judgments and assumptions about the study topic in order that they might authentically listen to the participants' perspectives and describe the essence of the phenomenon being studied (Carpenter, 2013). As Tufford and Newman (2012 b) state: "it is not a matter of simply articulating preconceptions but a process of self-discovery whereby buried emotions and experiences may surface" (p. 84) that, in my case, began before undertaking the research and continued throughout the research process. We decided to conduct a bracketing interview. This is a strategy "by which researchers are assisted in the self-discovery process by a colleague or co-researcher in order to explore the impact of their personal and professional experiences particularly during data collection and analysis" (Carpenter, 2013, p.124). According to Rolls and Relf (2006), the bracketing interview is a new method by which supervisors can support novice qualitative researchers. The process offers the novice researcher an opportunity to reflect and explore his or her personal responses within the context of the data and the supervisors to be constructively involved. The bracketing interview, during which the interviewer was the supervisor and the interviewee was the researcher, was

conducted in the supervisor's office and lasted 45 minutes. The interview session was audiotaped and transcribed. After the formal interview, other meetings were held during which the supervisors and I discussed the interview transcript content, identified emerging key issues and how these could be bracketed during the research process.

#### **3.6.4.1 Attaining bracketing**

These discussions focused on what could potentially influence my capacity to listen to my participants and the personal emotional responses that might make it difficult for me to manage during the data collection. During these discussion, it became clear to me how my religious beliefs, professional and personal experiences of caregiving, and the needs of children and parents, and what services should be offered to parents of children with cerebral palsy, could potentially cause me to judge the participants' perceptions and experiences. The following are examples of how the bracketing interview and subsequent discussions contributed to my reflexivity process:

- i) My personal understanding of caregiving focused on the provision of all the child's essential needs and the expectation that caregivers should train their children to be religious

*Simon: What do you mean by caregiving, caregiving process?*

*Giftly: Caregiving is the process of providing the needs of someone who is not in the position to do it by him or herself. How they cater for the needs of the children.*

*Simon: What do you mean in particular?*

*Giftly: General provision and support*

*Simon: Can you describe what you mean by general provision and support that you believe is caregiving. I want you to explore what caregiving means to you. What is your understanding of caregiving?*

*Gifty: Caregiving is a process when an individual provides food, shelter and activities of daily living to someone who is dependent. I believe that the caregivers should see the caregiving as their responsibility. It is the provision of the needs of the children. I expect caregivers should be able to identify the needs of the children and make an attempt to provide the needs.*

*Simon: What are these needs?*

*Gifty: Safe shelter and good nutrition, promotion of general health like grooming. Again the social needs of the child like playing and leisure. These are the things I expect a caregiver should give the child*

*Simon: What is your expectation based on, on your experiences?*

*Gifty: My expectation is based on my experience as a mother. As a mother I would like to provide everything that my child needs to make them comfortable, providing accommodation, good clothing, grooming, and train them to become good adults in the future. I believe that my children should be God fearing when they grow up. So as part of the training I pray with them, go to church with them and teach them the bible.*

Bringing into consciousness my expectation of caregiving helped me to better understand the assumptions that could have influenced the research process, particularly data collection, for example:

- a. I assumed that children with cerebral palsy would have some impairments which would limit their activities of daily living, that they might have special needs in addition to the care required by a typical child, and that the participants would discuss these in sharing their experiences of caregiving.

- b. My personal experience as a mother and professional experience as a physiotherapist caused me to ‘judge’ the quality of caregiving provided from competing, and frequently conflicting, perspectives. As a result, I experienced significant difficult and emotional responses that I had not expected particularly during the pilot interviews.
  - c. I came to realise that my cultural and religious beliefs about the caregiving role and process could restrict my ability to ask effective probing questions during the interviews.
  - d. In addition to how my Christian beliefs influenced the design and implementation of the study, I also assumed, based on the literature and my own experiences as a physiotherapist, that the religious beliefs of the participants of this study would influence how they construct the meaning of caring for their children with cerebral palsy.
- 
- ii) I struggled initially with concerns that my professional understanding of cerebral palsy and my clinical experience would result in a conflict between the role of researcher and therapist. Feedback from the pilot interview participants and discussions with the supervisor helped me to clarify and resolve any potential conflict.
  - iii) I experienced emotions after witnessing the deplorable situations that most of the caregivers were in. It came up during the bracket interviews and my supervisors encouraged me to bracket my emotions.

In summary, the following strategies contributed to the bracketing process:

- After transcribing the bracketing interview and exploring the issues that emerged with my supervisors, I recorded my personal reflections about the topic to ensure that I could make explicit the suppositions, biases, values etc that I held about the topic.
- The primary literature review was conducted after the interviews and data analysis process were completed in order to ensure that I was not unduly influenced by the preceding research.
- I kept a reflective dairy to document thoughts, assumptions and feelings associated with the research process and my relationship with the participants.
- The emerging themes and the process of imaginative free variation engaged upon during data analysis (described in section 3.7.2 step 4) were thoroughly examined with the aim of establishing the true essential structure of the phenomenon being studied.
- Each phase of the research is described in detail in the dissertation for the readers to promote trustworthiness of the findings and the research process.
- The supervisory team provided maximum support during the data analysis process and peer reviewed interviews transcripts, significant statements derived from the transcripts and the meanings assigned (described in the next section).

### **3.7 Data analysis**

In this section the chosen data analysis approach is discussed and justified as appropriate for this study and characteristic of qualitative research (Gibbs, 2008).

Carpenter and Suto (2008: 113), define data analysis as “the process of moving from raw interviews to evidenced-based interpretations that are the foundation for published report”. Many qualitative researchers have described the process as the most complex and mysterious of all the phases in qualitative research because it is difficult for one to know exactly what the researcher did during the analytical process and how generated data is transformed from raw data to new knowledge (Carpenter and Suto, 2008; Thorne, 2000). Qualitative studies rely solely on the researchers’ interpretations and constructions of the meanings derived from the data (Thorne, 2000). An active analytical process is demanded throughout the study and a critical understanding of the whole process is needed not only in the research process but also in reading and demonstrating understanding of the findings (Thorne, 2000:18). Hence Wollenhaupt (2010) recommends that qualitative researchers should provide their readers with a detailed account and explanation of the data analysis process and how they arrived at a coherent narrative. This section explicitly describes the detailed approach to data analysis that was taken in this study. The data analysis process involved two stages. In the first stage all the interviews were translated and transcribed and the second stage involved the application of Colaizzi’s method (Colaizzi, 1978) to generate the main themes.

### **3.7.1 Translation and transcription of interviews**

The generation of raw interview data marks the beginning of the data analysis process in qualitative research. In order for data analysis to proceed the audiotaped interview must be transcribed. Researchers across all disciplines have argued that transcription is the most important component of the analysis process and how it is done

can contribute to the rigour of a qualitative study (Bird, 2005; Lapadat and Lindsay, 1999; Poland, 1995). To ensure rigour, Poland (1995) recommends a routine review of the quality of the transcripts before the analysis of the textual data. Many authors have challenged the absolute true representation of the context of interviews when transcripts are not augmented with the field notes and reflections (Poland, 1995). The adjunct question is: How would the voices of the participants be read and understood as they wished them to be heard? Gibbs (2008: 11) opined that the “transcript will never be completely accurate” when compared to the interview context. Poland (1995: 291) agreed saying that: “The emotional context and nonverbal communication are not captured at all in the audiotape” and this may limit the quality of transcripts. With reference to the language used for the interviews, Squires (2008: 265) asserted that: “Failure to address language barriers and the methodological challenges they present threatens the credibility, transferability, dependability and confirmability of cross-language qualitative research”. Chen and Boore (2009) recommend that interviews be transcribed verbatim in the original language and then content analysis be conducted to generate themes. This should be followed by forward and back translation of the generated themes from the local language to English and finally an expert panel or committee needs to review the translation process and come to agreement on the translation in order to gain conceptual equivalence. The essence of this recommendation is that the analysis should be done in the original language and this was used in a number of the studies reviewed (Nikander, 2008; Huang, Kellett and St John, 2011). For the purposes of this study, translation was done prior to analysis. It was assumed that due to the complexity of concepts and idiomatic expressions in Akan language, which are very difficult to translate into English, it would be easier to translate



the original audiotaped interviews rather than performing the translation once the categories and themes have been developed (Twinn, 1997). According to Twinn (1997) the use of translation in phenomenological studies should be seriously considered as it could alter the fundamental purpose of understanding the essence of the phenomenon from the informant's perspective.

To ensure that some level of technical accuracy was achieved, I transcribed all the interviews (Birbili, 2000). Audio recordings in the Akan (Twi) language were translated into English before they were transcribed. For each interview, I recorded the translation at the same time as I listened to the original audiotaped interview and then transcribed my recording. I have experience of oral translation as I often provide interpretation for other local and international researchers visiting the university. The translation of the interviews were kept as literal as possible to preserve the conversational style and exclamations which are common in the Akan language. My aim was to render a translation that is as close as possible to the structure and format of the Akan Language. A bilingual speaker who is also a physiotherapist reviewed and checked the transcripts against all the original audio recordings for any discrepancy between the written record and the audiotape recording. This physiotherapy colleague was chosen because he is able to speak both Akan and English very fluently and he is sufficiently educated to be familiar with the concepts and the phenomenon being studied (Chen and Boore, 2009; Poland, 1995). The identities of the participants were not revealed to this colleague. The meaning of words and phrases that were identified as problematic or had discrepancies in meaning were clarified or removed (Birbili, 2000). In addition, the bilingual speaker selected three transcripts at

random and back translated them into Akan language. It was too expensive and time-consuming to back translate all the audiotaped interviews but doing three served as a strategy of rigour and ensured the accuracy and quality of the translation process. After transcribing the audiotaped translated interview I wrote field notes besides the narrative data (transcript) recording any relevant contextual information and non-verbal gestures that I acquired from participating in the interview. I also recorded in my reflexive diary after each interview my reflections and any other relevant information that I could remember during each interview session. Specific cultural issues that arose in the interview were also recorded and considered. The process was problematic as there are diverse schools of thought on the issue of translation of transcripts, and the whole process was complex and it required considerable time and effort.

There are a number of different approaches for analysing phenomenological data described in literature (Dowling, 2007). Ray (1994) expressed concern about the inappropriate ways that some researchers have applied the philosophical foundations of phenomenology in their data analysis process. The main challenge identified was the varied approaches found in literature. Hence the process of making a decision of the choice of approach and how to justify it could be confusing for the novice qualitative researcher. The basic principle is that one should be clear about which approach they are adopting (Crotty, 1996). Primarily, studies adopt methods that had been developed in a systematic fashion by phenomenologists and the authors are often influenced by the most widely adopted approaches in literature (Kuo and Lach, 2012). However, Hyener (1985), as quoted in Priest (2002:55), opined that sometimes phenomenologists are reluctant to

adopt specific step-by-step procedures in data generation and analysis for fear of losing the naturalistic characteristic and flexibility of qualitative research analysis. Conversely, it is useful for novice phenomenologists to use established step-by-step approaches for their analysis (Priest, 2002). Priest (2002) expressed concerns about claims made by novice researchers that they devised and implemented an untested approach to data management and analysis and considered findings identified by such methods to be questionable. Based on Priest's (2002) recommendation, a review of the most frequently used approaches, based on Husserl's descriptive phenomenology were conducted. The methods espoused by van Kaam (1966), Colaizzi (1978) and Giorgi (1985) met the criteria (Gina, 2012). The three methods use a sequential approach to arrive at themes that describe the experience of a phenomenon. The significant difference, which is vital to this study, is the issue of validation of the results (Gina, 2012). Colaizzi (1978) considers that the researcher should return the findings to the participants for validation; van Kaam (1966) recommends that experts should do the validation and, in contrast, Giorgi (1998) is neutral on the issue and considers it inappropriate in most cases to ask either the participants or experts for validation. Therefore Colaizzi's (1978) strategy was adopted for this study as it was difficult to get experts to do the validation as recommended by van Kaam (1969). Miller (2003:73) affirms "Colaizzi's procedural steps for data analysis provide a clearer guidance for a novice phenomenologist". A number of authors have published accounts of their data analysis process using Colaizzi's method e.g. Sanders (2003), Miller (2003) and Shosha (2012).

### 3.7.2 Applying Colaizzi's analytic method

Colaizzi's (1978) descriptive phenomenological approach was adopted to develop an essential structure of the phenomenon of caring for a child with cerebral palsy who had never received any form of rehabilitation. I chose this method because it gives a simplified step-by-step approach that guided me throughout the analysis process. The explanation of the steps of this approach provided by Shosha (2012) and Sanders (2003) enhanced my understanding of the data analysis process. The sequential procedure adopted was as follows:

Step 1: *"Acquiring a sense of each transcript"* (Colaizzi, 1978) which Shosha (2012 p. 33) further described as *"Each transcript should be read and re-read in order to obtain a general sense about the whole content"*

The process of recording the translation and transcribing the interviews helped me to immerse myself in the data, that is, to acquire a feeling about, and knowledge of, each transcript. However, I also read through the entire transcripts several times to gain a sense of the whole content. When reading through the transcripts, I was able to identify the assumptions, personal biases and values that came to mind and these were documented with the intention of bracketing them during the analytic process. I experienced significant feelings of empathy during this phase related to the rights of women and how they could be better protected in all spheres of life. These feelings clearly arose from my personal feminist values and desire to strive for gender equity and I made notes to that effect in order to bracket them during this process.

**Stage 2:** *“Extracting significant statements”* (Colaizzi, 1978) simplified by Shosha (2012 p. 33) as *“For each transcript, significant statements that pertain to the phenomenon being studied should be extracted. These statements must be recorded on a separate sheet noting their page and lines numbers”*.

Each transcript was given a code number and line numbers were assigned in order to make referring back to important statements easy during the data analysis process. Significant phrases were highlighted and copied into a table with the transcript code, line and page numbers in a new document. Judgements about the significance of statements were kept as broad and flexible as possible at this point to avoid missing any useful statements (Colaizzi, 1978). My supervisor who is experienced in phenomenology selected two transcripts at random and extracted the phrases she considered to be significant (Shosha, 2012). These were then compared and discussed and consensus was reached. I found this to be an important learning process that supported the analysis of further transcripts.

**Stage 3:** *“Formulation of meanings”* (Colaizzi, 1978)

At this stage Colaizzi (1978) recommends that the researcher restate the significant statements to thoroughly illustrate the meaning. I listened to the oral version of each translated interview and at the same time checked the significant statements developed for each transcript to ensure that all the important phrases were included. Meanings were formulated for significant statements in each transcript. Each statement, and the sense of meaning, was carefully considered in the context of caring for child with special needs.

Same or nearly same phrases were identified and deleted to avoid repetitions. After formulating the meanings for six transcripts, I submitted the significant statements and associated meanings to my supervisor for him to peer review to ensure that the meanings I had formulated were consistent with the significant statements I had identified. Although bracketing is recommended throughout the data analysis process, it is needed most in the process of formulation of meanings. My experience in working with caregivers helped me to understand the context and culture in which the caregivers were describing the phenomenon. Extreme caution was taken not to impose my suppositions on the meanings. Table 3.1 presents an example of the formulated meanings derived from more than one significant statement.

**Table 3.3 Examples of significant statements and their formulated meanings**

Transcript number/page /line number	Significant Statement	Formulated meanings
T2/2/24-29	We were moving from one place to another seeking for a cure but it was not yielding any result. When she was nine years old, her father sent us to see a herbalist who gave us some herbs to bath her. That was when we started seeing some improvement. She was very floppy but after bathing her with the herbs her muscles were becoming a bit stronger. She was now becoming stiffer, not floppy as she used to be. After that place I did not sent her to any place again.	Mother moving from one place to another seeking for a cure but it was not yielding any result
T2/2/ 39	We have been trying all sought of medications but none worked. At first my grand auntie showed me some herbs and I bought them from the market. That one I used it as enema, I did it several times but I did not see any improvement. Someone else also said I should	
T10/4/72-77	send him to a prayer camp. I paid 5 million old cedis , but they did all that they could but there was no improvement. Currently I don't have any money so I am not going to send him to any place again	

**Step 4:** “*Organising formulated meanings into clusters of themes*” (Colaizzi, 1978)

After formulating meanings for all the significant statements, I then began to map the meanings into theme clusters on a flipchart. Initially, the significant statements that most clearly described the respective meanings were mapped to a number of the emerging themes. Individual theme clusters of formulated meanings were assigned a colour. The process was quite slow as relationships between formulated meanings from different transcripts were being established, and abstracted from the transcripts of origin, to form themes during this phase. I then discussed the concept maps I had developed with my supervisory team in order to scrutinize the relationships I had established between the significant statements, formulated meanings, theme clusters and emergent themes to ensure that they were accurately linked. Twenty-six theme clusters were consolidated to form six secondary themes which were then grouped into two main themes.

According to Colaizzi’s (1978) method, validating the theme cluster is an important phase of the data analysis process. I achieved validation by examining the significant statements in each transcript and ensuring that they had all been accounted for in the theme clusters. The theme clusters were then re-examined to ensure that they were emerged from the data. The second part of this stage requires that the cluster of themes should be further collapsed into emergent themes. The emergent themes should be common to all the participants and it serve as the essential structure of the phenomenon being studied.

**Step 5:** *“Exhaustively describing the investigated phenomenon”* (Colaizzi, 1978)

In the fifth step, Colaizzi (1978) suggested that after creating the theme clusters and the emergent themes, the researcher should incorporate them into an exhaustive description of the phenomenon being studied. In accordance with Colaizzi’s method, I integrated the emergent themes into an exhaustive description of the phenomenon of caring for a child with cerebral palsy with the aim of ensuring that this description contained all the elements of the experience. Finally I submitted it to my supervisors for validation and they confirmed the richness and the completeness of the description.

**Step 6:** *“Describe the fundamental structure of phenomenon”* ( Colaizzi, 1978)

Step six is similar to step five. It is the reduction of the exhaustive description into a fundamental or essential structure. The fundamental structure consisted of the descriptions and meanings derived from the previous steps. In this phase all misplaced, redundant and overestimated descriptions were removed from it. The supervisory team comments were also included. The essence of the phenomenon is well understood through the process of free imaginative variation.

Free imaginative variation as described by Spiegelberg (1982) quoted by Dowling (2007. p. 133) as “a mental experimentation in which the researcher intentionally alters via imagination different aspect of the experience, by either taking from or adding to the proposed transformation”. The essential structure of the phenomenon of caring for a child with cerebral palsy living in rural Ghana who has never received any form of rehabilitation was finally achieved through the process of free imaginative variation. I



intentionally removed or added theme clusters and examined if with or without them, they would alter the understanding of the phenomenon. If without a theme cluster, caused the phenomenon from being 'what it is', then the theme cluster is an essential part of the phenomenon (van Manen, 1990). For example, the impact of the burden of care on the emotions of the caregiver was missing, when the secondary theme, 'feeling of despair and sorrow' was removed from the structure. The feeling of despair and sorrow was triggered by both personal and environmental factors associated with the care giving process. The essential structure revealed that all the secondary themes that emerged to form the main themes were influenced by both personal and environmental factors. In the process of free imaginative variation, I removed the secondary theme, 'feeling of despair and sorrow'. This alters the understanding of the phenomenon. Therefore the secondary theme 'feeling of hopelessness and profound sadness' addressed the negative impact of caregiving burden on personal factors, hence an essential part which should be included.

**Step 7: “Returning to the participants” (Colaizzi, 1978)**

Step 7 served as the final validation stage of the data analysis. The validation process started during the interview. After each interview, I summarise the key points to the caregivers and ask if they agree and were allowed to comment on the accuracy. Secondary the decision to return to the participants for validation as recommended by Colaizzi(1978) needed to be critically considered. For this study, all the participants were referred to the community based parent-training programme and began to receive information and guidance about caring for their children with cerebral palsy. This involvement in the training programme could have potentially changed the participants'

understanding of the caregivers' role or caused them to be concerned about the experience they discussed in the interviews. I assumed that the experiences of the participants might have changed after they had received some rehabilitation services for their children. Nevertheless after consultation with my supervisory team, a decision was made that I could return the data to the participants. Hence the participants were informed that the exhaustive description of the phenomenon, I planned to give them to review was a recall of their experiences before the intervention they are receiving. For the purposes of this study, the exhaustive description of the phenomenon was forward and back translated to Akan by the researcher, and the Akan version was audio taped since only two of the participants could read English. The voice recording was very audible and recorded slowly. All the participants were willing to be involved in the member checking process.

The date and time for the member checking process were fixed by the leader of the self-help group of the caregivers in consultation with the other members. The physiotherapist in charge of the outreach programme was also consulted because the caregivers proposed that the programme should be held during one of the group meetings. Ten caregivers who participated in the study, six new caregivers, the community health nurses and the physiotherapist were all present. I therefore sought for consent from the caregivers who participated in the study whether they were comfortable having the new caregivers to take part in the member checking. They all agreed and one affirmed "I don't think it is wrong for all of them to be present, we want the whole world to hear our story". The audio recording was played to the participants after seeking their consent. Participants were encouraged to ask me to stop the tape anytime they want to give a comment. The audio

recording of the exhaustive description of the phenomenon lasted 30 minutes. Within the first minute of playing the audio tape, one of the participants commented on the statement that the caregivers have the capacity to observe that something was wrong with their children. According to the participant, the statement was not comprehensive enough to account for the caregivers having their first child to be the child with disability. According to the caregiver such caregivers could not recognised any abnormality with their children, but it was their mothers who persistently announced that something was wrong with the child and they had to seek for spiritual intervention. Eventually all the participants expressed their satisfaction and attested that the results played to them represented an accurate reflection of their individual experiences. They had no concerns and provided only a few comments. The comments were incorporated in the discussion. The next chapter present the 2 main themes emerged, the secondary themes and the data clusters that inform the secondary themes. It also described the socio-demographic characteristics of the caregivers and the children.

## **Chapter 4**

### **Findings**

#### **4.1 Introduction**

The preceding chapter detailed the method and the process of enquiry used to achieve an in-depth understanding of the phenomenon being studied. The research question was: “How do individuals who care for children with cerebral palsy in a rural Ghanaian context but who have not received any form of rehabilitation, experience the caregiving role”? The analysis process was structured according to the sequential method developed by Colaizzi (1978). My intent in this chapter is to provide a comprehensive description of the caregivers who participated in the study in order to promote future comparison and transferability of the findings with similar people, settings and times (Johnson, 1997). This chapter therefore presents the socio-demographic characteristics and contextual factors of the caregivers and the demographic and clinical profile of their children with cerebral palsy who were involved in this study. In order to promote the ‘voices’ of the caregivers, each theme is illustrated and supported by example significant participant statements.

#### **4.2 Socio-demographic characteristics of caregivers**

A total of 12 caregivers comprising 2 males and 10 females were recruited for this study over a period of 6 months. The socio-demographic characteristics of the participants are presented in Table 4.1. Pseudonyms are used to ensure the anonymity of participants and their children. The participants’ identified themselves as being the primary caregiver of a child with cerebral palsy. The participants’ ages ranged from 22 – 68 years. Two

individuals did not know the year they were born, so I estimated their ages based on significant past events in the country. For example, one of the participants (Akua) mentioned that she was informed by her mother that she was born around the time there was great famine in the country (1983), hence her age was estimated to be in a range of 30-35 years and Nana was born before independence (1957). The participants' education level varied greatly: eight caregivers had never been to school, two had only primary education, one secondary and one had a university degree. Seven participants were not employed, one was a health professional, three were engaged in small scale trading and one was a farmer. Eleven participants were Christians and only one was a Moslem. Eight of the participants were the biological mothers of the children; two were grandmothers, one a biological father and one a cousin.

Nine of the caregivers, including the two grandmothers and the two men, indicated that they were married, but only one of the biological mothers among the married participants spoke of the involvement of their spouse in providing direct care to the child with cerebral palsy. Three specified that they were married but not living with their husbands. According to these three caregivers, their husbands left home without informing them and they have no idea as to their whereabouts. The two grandmothers among the caregivers indicated that their husbands were the heads of the household but were not involved in caring for the child. The three caregivers who were the biological mothers of the child with cerebral palsy and single explained that the fathers of their children had not yet performed the marriage rites.

### **4.3. Contextual factors of caregivers**

My motivation for including this section in the thesis is to provide readers with a vivid description of the unique contextual factors of the participants. Shenton (2004, p.63) explains that such sections are important as, “to allow transferability, qualitative researchers should provide sufficient detail of the context of the fieldwork for a reader to be able to decide whether the prevailing environment is similar to another situation with which he or she is familiar and whether the findings can justifiably be applied to the other setting”.

**Table 4.1 Socio-demographic characteristics of caregivers.**

<b>Name</b>	<b>Sex</b>	<b>Age</b>	<b>Number of children</b>	<b>Marital status</b>	<b>Level of education</b>	<b>Religion</b>	<b>Employment</b>	<b>Relationship with the child</b>
Kofi	M	46	5	Married	None	Christian	Farmer	Cousin
Afua	F	39	3	Married	Primary	Christian	Trader	Mother
kwaku	M	44	2	Married	None	Christian	Unemployed	Father
Akua	F	30-35	1	Married	None	Christian	Unemployed	Mother
Adwoa	F	28	3	Single	Primary	Christian	Unemployed	Mother
Esi	F	33	4	Married	None	Christian	Trader	Mother
Mena	F	48	3	Married	None	Moslem	Trader	Mother
Eno	F	31	2	Married	First Degree	Christian	Health professional	Mother
Awo	F	68	7	Married	None	Christian	Unemployed	Grandmother
Akosua	F	22	2	Single	None	Christian	Unemployed	Mother
Abena	F	23	1	Single	Secondary	Christian	Unemployed	Mother
Nana	F	Over 60	9	Married	None	Christian	Unemployed	Grandmother

This section will also provide a better understanding of the connections between the ‘lived experiences’ of caregivers and the contextual factors as well as the physical conditions in which the caregivers live. Six participants were living in rented accommodation within an extended compound occupied by 7-15 other families. Two lived in their own homes; another two lived in homes built by their husband, one by the parents and one in government accommodation. Four of the caregivers did not have a kitchen in their house so they cooked on the porch in front of their rooms or under a hut in the

compound of the house. Only one participant used a stove for cooking. The rest used coal-burning pots. Only three participants had piped water in their homes. Six had to buy water from a neighbour and three had to depend on hand dug wells. Nine of the participants had toilets in their homes whilst two had to use a nearby public toilet for a fee and one participant had to walk for about 3 minutes to a free toilet facility. All the participants had bathrooms in their homes, three shared their bathrooms only with their nuclear families and two shared with their own extended families and seven had to share with other families. None of the participants own a car and they have to depend on the public transport, which is more regular during the market days of their respective towns. Most of the caregivers mentioned that they do most of their errands in town during the market days, which is two fixed days in the week and varies from communities. During the non-market days they have to depend on taxis.

#### **4.4 Demographic and clinical profile of the children**

The ages of the children ranged from 2 years 9 months to 14 years. Five of the children were females and 7 were males. None of the children went to school. Seven of the children had one, two, or three siblings living with them in the same house. Three out of the seven siblings were older than them and one child was in the middle of two siblings. Two were only children and the two children living with their grandmothers were the only children in their respective houses, the one living with the cousin was older than the last born of the cousin's five children. The participants all explained that the older siblings actively supported caring for the child with cerebral palsy.



Based on the participants' descriptions, the children were grouped as mildly, moderately or severely impaired but no formal assessment was conducted as it was considered inappropriate to the nature of the investigation. A mild impairment was defined as the child could move without assistance and his or her activities of daily living were not significantly limited (n=1), Moderate meant that the child needed assistance and the use of adaptive devices to accomplish daily activities (n= 4) and a severely impaired child required a wheelchair for mobility and was fully dependent on the caregiver for survival (n=7), however, none of these children had a wheelchair. One child was kept in an old car seat and another one in a baby walker despite the fact that he was eight years. The other five children were always laid down or sat on the caregivers' laps during feeding.

According to the participants all their children had one or more co-morbidity commonly associated with cerebral palsy. All the children cared for by the participants had communication challenges. Three also had a hearing impairment, eight had seizures but none of them were on orthodox seizure medication, four children had visual impairments, eight had difficulty in feeding and seven had urinary and/or bowel incontinence. The participants reported that their children had experienced more than one hospitalization for eye surgery (n=1), malaria (n=12), diarrhoea (n=6) and convulsions (n=3). None of the children had been involved in any form of rehabilitation. One caregiver mentioned that her child had received some exercises from the physician assistant in the hospital where she worked but she could not describe these in any detail.

#### **4.5 Overview of major themes**

The participants created the meaning of their lived experiences of caring for a child with cerebral palsy based on their interpretation of the condition. Each of the caregivers held a different set of beliefs that informed their actions. The themes that emerged from the data illustrate a link between beliefs, attitude and practices. Caregivers' experiences of caring for a child with cerebral palsy were much more complicated and full of desperation than those associated with caring for a child without disability in the same context. Analysis of the data revealed two main themes that represent the essence of the meaning of the caregiving process common to all the participants. The two themes reveal the internal and the external influences that shape the caregiving process. The emergent main themes were: Developing personal beliefs to support the caregiving role and the demands that shape the experience of caring and these will be discussed in depth in the remainder of this chapter.

**Table 4.2: Main themes, contributing secondary themes, theme clusters illustrating the lived experiences of caregivers of children with cerebral palsy**

Main Themes	Secondary themes	Theme clusters
Developing personal beliefs to support the caregiving role	Interpretation of the child's condition through religious and spiritual beliefs	<ul style="list-style-type: none"> <li>Perceived cause of condition is spiritual</li> <li>Committed to caring because of benefits and blessings from God</li> <li>Hope for the future because of religious belief</li> <li>Acceptance of condition because of the belief that it is given by God</li> <li>Coping supported by religious belief</li> <li>Beliefs in spiritual intervention</li> </ul>
	Perceived standard of care	<ul style="list-style-type: none"> <li>The nature of caring</li> <li>Strategies to improve condition</li> <li>Protecting child</li> <li>Estimation of recovery</li> </ul>
	Feeling despair and sorrow	<ul style="list-style-type: none"> <li>Acknowledging the child's developmental delay</li> <li>Lack of understanding of condition resulted in hopelessness and profound sadness</li> <li>Perception that child is experiencing pain and suffering</li> <li>Frustration</li> <li>Feeling stigmatised</li> </ul>
The demands that shape the experience of caring	Physical demands	<ul style="list-style-type: none"> <li>Difficulty in handling child causes exhaustion</li> <li>Managing other responsibility</li> <li>Lack of assistive devices for transfers and mobility</li> <li>Lack of physical support</li> </ul>
	Financial demands	<ul style="list-style-type: none"> <li>Cost of caring</li> <li>Give up work to look after child</li> <li>Lack of money for basics</li> <li>Lack of financial support from spouse and family</li> </ul>
	Social influence	<ul style="list-style-type: none"> <li>Informational conformity</li> <li>Attitude of others</li> <li>Social support</li> </ul>

#### **4.6 Main Theme 1: Developing personal beliefs to support the caregiving role**

The theme entitled 'Developing personal beliefs to support the caregiving role' was revealed in the participants' narratives of caring for a child with cerebral palsy. The

caregivers' described lives that were built on their personal beliefs and how every action they took was influenced by specific beliefs or perceptions. Eno, a health professional and a caregiver said, "I think these beliefs are inbuilt in us, nothing can change them". There is a particular focus within this theme on the importance of the participants' religious beliefs in particular that God controls every aspect of their lives whether the outcome is good or bad. Most of them expressed that their perceptions of their child's situation and beliefs about cerebral palsy developed from the information and advice they received from people they considered had knowledge and experience about the condition. Their beliefs also influenced how they evaluated the standard of care they provided for their child and lastly, how they judged other people's behaviour and attitudes towards their children with cerebral palsy. The following secondary themes contributed to the development of this main theme and will be discussed in detail below:

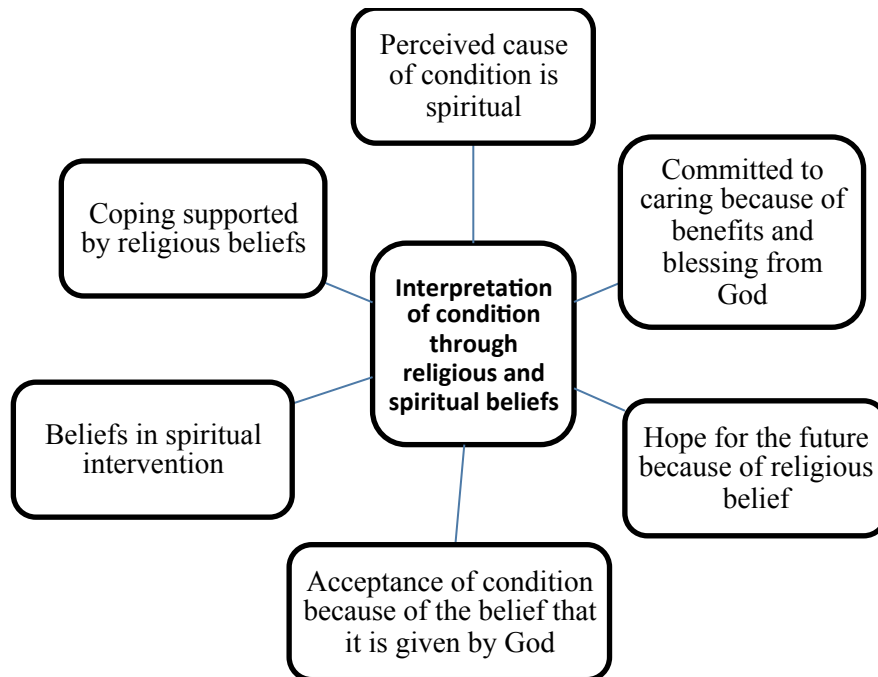
- Interpretation of the condition through religious and spiritual beliefs
- Perceived standard of care
- Feelings despair and sorrow

#### **4.6.1 Interpretation of the condition through religious and spiritual beliefs**

The participants all expressed that they recognised that something was 'not right with their children' and that they had a serious health issue when they observed their child's delay in achieving the developmental milestones as compared to other children of the same age. Some of the caregivers perceived that something was wrong with their child

right from birth. For example, one caregiver said: “What I know is that when I gave birth to her she was not strong, she was floppy”. Only one of the caregivers was aware it was cerebral palsy. For all the participants, understanding what was wrong with their children was very significant in the caring process. Inability to get an explanation of the condition caused most participants to conceptualise it as a condition with a spiritual cause. In describing their experiences of caring for the child with cerebral palsy the participants frequently interpreted the condition through the lenses of their spiritual and religious beliefs and a distinction between these types of beliefs was established in individual accounts. Religion was usually expressed in terms of their conduct and the rituals they performed in order to achieve the optimal relationship with God. Spirituality, being a broad concept, accommodated many perceptions about the process of searching for, and expressing the meaning of their children’s condition as coming from, a divine origin. There was a sense of spiritual connectivity in their lived experience of the caregiving process as they expressed things happening in the spiritual world instead of the physical. An overview of the data categories that contributed to this secondary theme is provided in Figure 4.1 and will be discussed in more detail in the following section with supported quotes from the participants.

**Figure 4.1: Contributing data cluster of secondary theme: Interpretation of condition through religious and spiritual beliefs**



#### **4.6.1.1 Perceived cause of condition is spiritual**

The participants were asked in the interviews to share their beliefs and understanding of their child's condition. The purpose of exploring caregivers' interpretation of cerebral palsy was to understand the foundation on which the caregivers built the meaning they attributed to the phenomenon of caring for their children. The resulting descriptions of cerebral palsy and how it affected their individual children varied. Some of the caregivers believed that their child's condition was a form of spiritual sickness that affected movement and communication. For example, Kofi said:

She cannot walk well, difficulty communicating with her, everything about her shows that she is a sick person. She is not like the others. Witches brought about her spiritual illness. It is said that when she was born, someone came and said the baby was beautiful and that she had a bright future. It was after that the sickness came on her (T1ss13)

Similarly, Afua developed a spiritual interpretation when she disagreed with the professional opinion of doctors she consulted. She appropriately based her own opinion of her child's condition on the differences in developmental milestones between her child with cerebral palsy and the twin sister she had observed since they were a year old. As she explained:

When they were one year old, a lot of people advised me to send her to the hospital, which I did I sent her to Akomeya Hospital. The doctor there just prescribed medicine for her but he told us that there was nothing happening to her, just that the sister was developing faster than her. She was still the same, people kept on advising us to send her to the hospital so when they were four years, I sent her to Koforidua hospital but the Doctor said she will be alright. I did not understand, her sister was talking, walking, and had even started going to school, she was just lying down, she could not even sit, nor talk, but still the doctors were telling me that she will be okay. I got to know that it was not a sickness that can be treated in a hospital and it must be spiritual (T2 ss34)

Afua concluded that the child's condition had a spiritual origin because doctors at the hospital were unable to give a physical explanation for the abnormalities. Afua analysed the discrepancies between the doctors' opinion and her own and concluded that the source of the problem must be beyond the physical. This reveals how individuals try to resolve conflicting information in order to develop a logical understanding of a situation and form their own conclusions. In contrast, Esi came to the conclusion that medications given to her child in the hospital could have caused the condition:

When my child was three months old, she wasn't feeling well, so I took her to the hospital after which they gave her some medications

and she was discharged. After that all these things happened, she couldn't do anything on her own. She was down and weak. I believe the medicine has caused the condition (T6ss3).

It was evident that most of the participants lacked the accurate information that they need to correctly interpret their child's condition. In contrast, Eno, who was a health professional, had access to some medical information and consequently interpreted the condition more appropriately:

The doctors told me that he is having cerebral palsy and I also learnt something little from the Internet. From what I read, it is a problem of part of the brain responsible for muscle coordination. His muscles are very stiff especially the left side and he can't use it. He can hold things very firmly with the right one but the left one has a problem (T8ss1)

However, Eno also discussed her experience of receiving very little useful information and needing to independently seek for other resources.

#### **4.6.1.2 Beliefs in spiritual intervention**

Participants all described the challenges they experienced in seeking information about their child's diagnosis and possible interventions to improve their function. Once they arrived at their own understanding of the condition they then struggled to come to terms with the diagnosis and sought for approaches to remediate the child's problems. For example, Kwaku, a father of an eight-year-old child with severe cerebral palsy described his experience of beginning his search for a solution with a herbal doctor and ending by consulting church representatives. Initially, Kwaku had confidence that these interventions would work because he had heard testimonies from others.

The first herbal doctor we saw told us that the condition was spiritual so he has to bath him with some concussion and they used another one to spread it all over the body. Later they said they have to cut some of his hair and put it in a river.....The last place I went is the



Synagogue church. There they did not demand money but they gave us some holy water to use. I know that this might work. I have been hearing testimonies from others who have been using the anointing water and it had worked for them. Some had instant healing and others too get it gradually over some years. (T3ss4,16)

Akosua was convinced that her son had been attacked by ‘the evil one’ and specifically targeted because he had a bright future but she was optimistic that it would be resolved by her praying for his recovery. As she explained:

I don’t know. Maybe it is from the evil one so when I continue to pray he may be well. When the evil one gets to know that a child has a bright future, he then destroys the child. It is the evil one. (T10ss4)

Similarly, Adwoa believed that her child had cerebral palsy because someone admired the child’s beauty:

Initially she was not convulsing like this, but there was a day when someone said she was pretty and ever since that day, she started convulsing. I went around looking for a solution and I was told that because of the cause it is only prayers that could cure it. (T5ss32)

In contrast, Akua believed that her child was born with cerebral palsy because she did not seek divine protection when she was pregnant and felt her responsibility was to pray for the child’s recovery:

Yes, I try my best to improve the care to correct that mistake (of not seeking divine protection). So it’s prayers that matter. I have learnt from this and I will make sure I do not repeat this mistake. Next time when I am pregnant, I will seek divine protection. (T4ss19)

Interestingly Eno, although being a health worker, still believed that cerebral palsy originated from a spiritual context and therefore required spiritual intervention.

It hasn’t been easy, even though I am a health worker but at first, it got to a time that we attributed the illness to be of spiritual origin or

problem, so we had to take him to a pastor for prayers and fasting. But it didn't work. (T8ss2)

#### **4.6.1.3 Coping supported by religious beliefs**

Participants described their conscious effort to apply the principles of their religion to solve their personal problems and minimize or accept the burden of caring for their child with cerebral palsy. According to the participants, the best way to cope with the challenges in caring for their child was to stop thinking about it. In the real sense, this can be seen as a form of denial. A number of the participants personalized the burden of caring, for example, Afua described the caregiving process as creating 'many difficulties' in her life and as the cause of 'bad things happening to her:'

I have been through so many difficulties but because I am a Christian, I don't want to keep on thinking about all the bad things that is happening to me. I have to endure it and move on. If I allow things to bother me, then I cannot care for her. I just take things as a routine (T2ss30).

It was clear that for many of the participants the main strategy for coping in the role of caregiving was to disregard the difficulties and continue with their lives. Adwoa described how she prayed and read the Bible as a means of diverting herself from the challenges and impact of caregiving on her life. As she said:

Yes at times I do cry and ask God why all this is happening to me, sometimes I tell God that he should allow me to be able to mingle with people, then I open the Bible and read and I forget about them (T5ss48)

Another coping strategy Adwoa used was to consciously remember past experiences of feeling she had been healed by God and she was optimistic that God would intervene again

and, to that aim, she tried to encourage her son's belief in God so that he could cope with his sister's disability and lack of independence.

I feel bad but I am someone who does not get discouraged easily so I will call him (older son) and tell him that the Lord's plans are not ours so he should not get frustrated that his sister cannot walk, he should rather be playing with her. I have also been paralysed before but the Lord gave me strength to walk again (T5 ss 72)

Adwoa also recounted how 'denying' her daughter's condition was positive in helping her to recover when she attempted suicide:

Initially, I felt like drinking poison to die, but now that I am used to her I do not feel that way again. I have realized that it is God who gives and He is the one who heals as well. So even if I go out and someone tries to discourage me, I always have it behind my mind that the Lord will heal her. Previously, I used to think about it a lot, but not anymore (T5 ss42)

#### **4.6.1.4 Acceptance of child's condition because of the belief that it came from God**

A total acceptance of the child's condition was evident in the participants' narratives and based on their belief that the condition and their subsequent caregiving role came from God. As Eno said: "But I knew that if it is God's will, then let his will be done, if it is something which is supposed to happen, it has happened". This unswerving belief in God's will was more evident in situations where the child with cerebral palsy was a twin. In these situations, participants believed that God had given them two things, one bad and one good. Afua, a mother of a thirteen-year-old child with severe cerebral palsy, elaborated how she was ignorant about her child's condition and attributed this to the dual nature of God's 'gift'. She explained it as follows:

I don't know anything about the cause or what is happening to my daughter. I don't understand anything. As for this sickness I don't understand. I have been telling myself that if God has given me two things, one good and one bad, should I tell God that I like the good one but not the bad one? I have to like both the good and bad. I will use the good one to console myself (T2ss42).

Kofi had a similar view, believing that his cousin's condition was God-made and as a result he had to accept it and the impact on his life saying "Oh for her, just as God has made her she should accept it like that. She is a sick person; I have accepted it that way (T1ss 29)".

#### **4.6.1.5 Hope for the future because of religious belief**

The participants' gained hope from their religious beliefs for the future of their child with cerebral palsy. As a result of their faith in God, participants were optimistic that God would heal their children and that their children were destined in the future to become prominent persons in society. Even Eno, who was a health professional, held the same pervasive belief in God's influence:

I know he has a future. That is the maternal instinct, one day my son is going to be a great person. I know through faith everything that we wish for will come to pass. I see my son becoming a medical doctor in future. If he becomes a medical doctor, I will ask him to specialize in neurology so that he can also care for children like him (T8 ss51)

Pastors, who were considered men of God, also reinforced the participants' faith by making positive prophecies about their children's future. Kwaku described how the pastors encouraged his belief in his son's future:

Since almost all the Pastors we've seen have reassured me that this my son will be someone important in future, I want to do everything possible for this child to walk and go to school...I believe that

because wherever we sent him, especially the spiritualists and the traditionalist, they all confirm that my son will be great in future and that is what the evil one has seen and has put all these sicknesses on him (T3ss17).

For most of the participants achieving developmental milestones was how they evaluated their child's potential for a brighter future and specifically prayed to God to enable them to observe the significant developmental changes they fervently desired. For example Awo, the grandmother of a four-year-old child with severe cerebral palsy, described her expectations and linked achievement of these to the mercy of God:

I don't think about her future, because, my prayer is that God should help her to walk, and should be able to hold a pencil and write. If she is able to do these two things, I know she will have a bright future. God will have mercy on her. She is very intelligent (T9 ss 20).

#### **4.6.1.6 Committed to caring because of benefits and blessings from God**

During the interviews, the caregivers explained how the anticipation of benefits and blessings from God supported their love and commitment in caring for their children with cerebral palsy. The caregiving role, enacted fully and to the best of their ability, was perceived as doing well in the eyes of God. Kofi explained why he believed that he would receive blessings from God as follows:

**Kofi:** I take her as a sick person so I don't get upset with her.

**Gifty :** Why do you say she is a sick person?

**Kofi :** Because she cannot walk well, having difficulty in communicating with her, everything about her shows that she is a sick person. She is not like the others.

**Gifty:** So right now what gives you the strength to keep on caring for her?

**Kofi:** It is because I have considered her to be a sick person.

**Gifty** : So what benefit would you get for caring for a sick person?

**Kofi** : I will benefit from God, I will get blessings from God.

**Gifty** : Oh okay! And please have you heard if someone had that benefit before? What gives you that faith?

**Kofi** : I have heard that if you do good, you will be rewarded with good and if you do evil, you will be rewarded with evil.

(T1ss, 12,15,16)

The participants considered that God's blessing would be attracted as a result of the child's condition and that the most likely way in which God would demonstrate his blessing would be through financial support from other people in the community. As Akua explains:

People like this (children with cerebral palsy) when you have a good heart and you are caring for them, even if you do not have what to eat; God will use somebody to bless you to be able to feed your family because of their condition (T4 ss30)

Another form of reward that participants discussed was having a relationship with important individuals in the society. Eno believed, that because of her child's condition, the president would one day visit her home:

Archbishop (name withheld), I was in my house when he knocked at my door – he was coming to visit my son. The nuns told him that one of the twins is disabled, so he just came to visit and to pray for him, misfortunes could sometimes turn out to be blessings. It could be that because of my son, one day I will be there and the president will knock at my door (T8 ss 5)

The participants all considered that they had established a strong relationship with their children and that it was a curse to give birth to a child and then refuse to care for them.

Akua described the core of her commitment to caring and to her son as follows:

I understand it (caring) in the sense that the Bible itself has told us that when we give birth and we do not take care of the child it is a

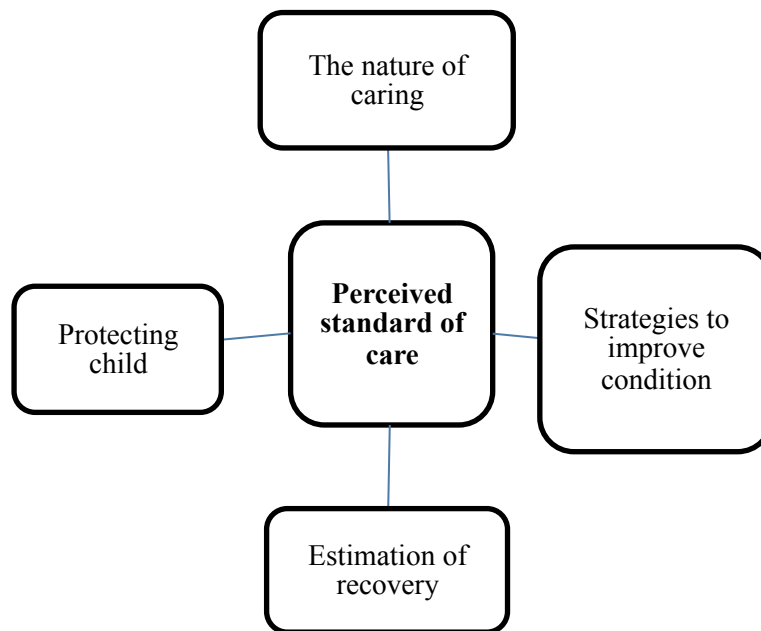
curse, hence, so far as I have brought the child into the world, whatever he needs, it is my responsibility to provide it (T4ss8).

Similarly, in Adwoa's opinion every child should be considered a blessing from God. As she said: "Children are blessings from God and not Satan so every parent should take very good care of their children and God will bless them."

#### **4.6.2 Perceived standard of care**

This section presents the second secondary theme under the main theme of 'Developing personal beliefs to support the caregiving role'. The participants' narratives revealed the different means they used to determine what caregiving should be. Four data clusters supported this secondary theme and are presented in Figure 4.2.

**Figure 4.2 Contributing data clusters of secondary theme: Perceived standard of care**



#### **4.6.2.1 The nature of caring**

The participants' understanding and motivation for assuming the caregiving role included caring in the absence (most commonly the death) of the biological mother, reflected in the following statements: "Caring for the sick person is an act of doing good", "caring because I am at home and not doing anything", and "caring because parents are too worried about the child's condition". The rationale of "caring because I have given birth to the child" was, not unexpectedly, expressed by most of the biological mothers in the study. They also indicated that the pain and trauma they experienced during pregnancy and delivery had contributed to the love they developed for their children.

The participants articulated a common understanding of the nature of caring. For example; Kofi described the nature of caring as "I mean it is difficult caring for them



(children with cerebral palsy) and it is about suffering, caring is putting up your best and when you are taking care of children you should be extra careful so that the child does not hurt himself". The central element of caring was the provision of the needs of the children with cerebral palsy. As Kwaku stated: "To take care of a child, we are providing everything the child needs". Provision of food and assisting them with feeding and bathing were the most common needs of the children discussed by the participants. In addition to the provision of these fundamental needs, the caregivers also monitored their child's hygiene and dressing particularly the children who had gained a level of functional independence. For example, Kofi described his perception of his caregiving role as:

I care for them and I provide everything for them...Oh in everything, for instance if she says she is hungry or we realize she is hungry, we give her food. She (the child with cerebral palsy) sometimes does some of the things independently. Sometimes I tell her in the evening to fetch water and take her bath, in cases where the water is beyond her reach, she tells us to fetch it for her (T1 ss 5&6)

Awo, in discussing her caring role and responsibilities, included helping the child decide what he or she would like to do on a daily basis, that is, trying to respect the child's autonomy: "If you are caring for someone it is not just about the person's feeding, bathing etc., you are responsible for everything the person would like to do or needs (T9 ss 7). Eno expressed concern about parents who preferred caring for their 'normal' children and, in her opinion, neglected the child with disability:

They (children with disability) need our care, we have to bath them, cloth them, always provide their needs, but many parents seem to care more for the normal babies than the disabled ones. They concentrate more on those who don't need them (T8 ss50).

She elaborated further by discussing the attitudes and practices she considered essential characteristics of a caregiver and the reasons mothers with children with a disability should devote time specifically to them. As she said:

Just be patient with the child, it takes prayer and determination, it is only through prayer that you can care for a child with cerebral palsy. Mothers should spend more time with their children who are disabled than the apparently normal ones. Because they survive on the love and affection of their parents and that keeps them going (T8ss49).

Similarly, Akua considered that the most important attribute of a caregiver is patience and love because the child with a disability is also “a human being”, just like someone who she identified as ‘normal’ As Akua explained:

For now because of his problem, he needs someone who would be patient with him, someone who will love him unconditionally, someone who will not abandon him because he is also a human being. You must always bring him close to your side and show him love just as you will do if he was not having this condition (T4 ss 9).

Participants expressed a clear understanding of why they were the people caring for children with cerebral palsy. For example, Kofi accepted the familial responsibility of caring for his cousin after the death of her biological mother:

My younger sibling, she is my mother’s younger sister’s child (cousin). But they are all deceased (Kofi’s mother and the mother of the child with cerebral palsy) so I am the one taking care of her (T1 ss 1).

This reveals the support that the extended family system can provide when there are no governmental support systems available. Interestingly, none of the participants expressed their expectation to receive any support from the central government. Both participants

who were grandmothers reported assuming the care of their disabled grandchildren in order to alleviate the mother's stress and burden of care. As Awo explained:

When she was delivered, I was staying with the parents, it was not even up to one year, when we detected she was sick, her mother was very worried about it, because of that I decided to adopt the child, so I have been caring for her for the past three years (T9 ss 1&2).

#### **4.6.2.2 Strategies to improve condition**

All the participants instinctively knew that their child had problems at an early stage in their development, and without official medical or rehabilitation support, proactively assumed responsibility for developing strategies aimed at improving their child's condition. Several caregivers reported that they were not able to identify the actual health condition of their child nor were they provided any information about cerebral palsy. As a result, they all employed strategies based on local remedies and ideas grounded in their own or others' experiences and beliefs. Their motivation of employing a particular remedy was their quest for recovery for their children, lack of understanding of cerebral palsy and the general prerequisites for normal motor development. For example, Akua explained that she does not celebrate her son's birthday because she believes that it is a form of pampering the child that would prevent the child from developing. As she explains, she expected the child to make an effort to achieve developmental milestones:

Since I gave birth to him I haven't bought an egg for him on his birthday because he is not able to walk...I feel because he cannot walk, I should not be pampering him. That might keep him on the ground and he will remain crawling...I do not know what I will do for him this birthday, maybe tomorrow God will provide before I will know it (T4 ss37)

Most of the participants had chosen to eliminate certain ingredients from the child's diet that they considered might be detrimental and cause the condition to worsen. For example;

Adwoa said:

Giving them [children with cerebral palsy] food with salt and sugar weakens them more. You see too much sugar can bring about stroke...Because when she takes the cassava then the convulsion occurs, hence any child with convulsion is not supposed to eat cassava and salt (T5 ss 61& 64).

Adwoa's child also had epilepsy and she was equally lacking in accurate information about this additional condition, for example, she believed that mentioning the word 'convulsion' would trigger an attack. She explained her strategy to prevent convulsions as follows:

I pray it [convulsion] does not come, hence I do not mention the name of the sickness again. When you mention the name, it occurs frequently. So if I go to a gathering and someone mentions it, what I normally do is to rebuke it with the name of Jesus. So I do not mention it at all for my child to have an attack and if not for this interview, I would not have mentioned it (T5 ss 66)

In general it was revealed that the strategies or remedies employed by the caregivers were based on pre-existing beliefs not only related to cerebral palsy but to other situations of life as well and were an attempt to 'try to deal with the situation'.

#### **4.6.2.3 Protecting the child**

In the interviews participants discussed their concern that their children with disability would be abused by other people and how they tried to prevent this type of abuse. They explained how they had to refuse suggestions of interventions from others that they considered would have negative effect on their children and how they worked to protect them. For example, Kwaku shared the following experience with a herbal doctor:

The first time he saw my child he told us that the condition was spiritual so he has to bath him with a concoction and they used another one to spread it all over his body. Later they said they have to cut some of his hair and put it in a river. That is when I told them that I will not agree and I can't go that far because I know rivers have some spirits attached to them, and if I allowed them to do that they can send my child into another world. I will never agree to things that will cost me the life of my child (T3 ss 4&5).

Adwoa described how she gained strength from God in responding to people who tried to pressure her to get rid of her child. Akua developed her own logical argument when faced with people who said her child was an animal that should be left in the bush. As she explained:

Some people (family members) say this illness is from the devil, They have been saying a lot about this kind of condition; they said he is a snake, and I should send him to the forest then cook and leave the food with him then the fetish priest will shoot and the child will turn into a snake and vanish into the bush. I refused to do that to my child. I do not believe in all these things because I got pregnant and delivered my child so I do not need anyone to tell me he is an animal. I know I gave birth to a human being (T4 ss23).

Afua's child was unable to talk but she was aware of her surroundings and reacted to people's attitudes and Afua protected her child by not discussing issues about her condition in her presence. As she said:

When people see her in front of the house, they stop to discuss her condition with me then she starts crying. She can understand everything. Especially when my neighbours come and express their worry about the fact that she cannot do anything. She has also prevented me from going out because then, she would start crying. Because of this I don't like people discussing her condition in her presence (T2 ss 14).

Most of the participants described how, in the early years of caregiving, they strongly resisted any attempts or advice offered by others that they considered would harm their children but, as the years past, they regretted not accepting more of the advice given to them. Afua explained how the relationship established with her child now makes it impossible to harm her:

I should have listened to them [people who have been advising her to get rid of the child] earlier, but now I am so familiar with her, I am very used to her. She also likes me. Now it would be difficult to send her away (T2 ss36).

Eno regretted her lack of courage in the early years in not taking the opportunity to try specific remedies offered to her as, in hindsight and on reflection, she felt they might have been of benefit for her child:

I was afraid they (extended family members) may be thinking I have a hand in it that is why I am refusing to see the pastors and traditionalists. Some people even went as far as requesting me to send the child to Kpando [name of a town], that far place to see a fetish priest, for him to give my child a concoction that will help him to walk. I wasn't bold enough, I will say I am a coward; I wasn't bold enough to even take my son there. Many people took their children there and they became better, they were bold (T8 ss 23).

#### **4.6.2.4 Estimation of recovery**

For many participants, their child achieving the ability to walk was their primary outcome and estimation of recovery. They felt that their child being able to walk would make them happy and decrease their stress. As with other participants, Awo shared her

anxiety about her granddaughter's future, if she continued to be unable to walk. As she said:

Sometimes I also ask myself, if this child is not able to walk, what will she do? She will be a burden on people. Even if she could at least take some steps, which are not like normal steps, I will be happy because my difficulties and fatigue will be over. Then she can bath herself and other things. That is my expectation...I will only have peace if she is able to walk. She can talk, everyone understands her, the only problem is the walking. She is now heavy, but in everything you have to carry her, you have to always lifting her (T9 ss21, 26).

Similarly Afua, the mother of a child with severe cerebral palsy and multiple co-morbidities, explained how the tasks of caregiving would be so much easier if her daughter could simply be able to sit independently but she had little hope of such recovery being possible. As she said:

Once she was still alive and in my hands, there was nothing I can do about it. I have taken it to be a normal daily routine, I am just praying that she can even sit, not necessarily walk nor talk, and I will be free for a while (T2ss19).

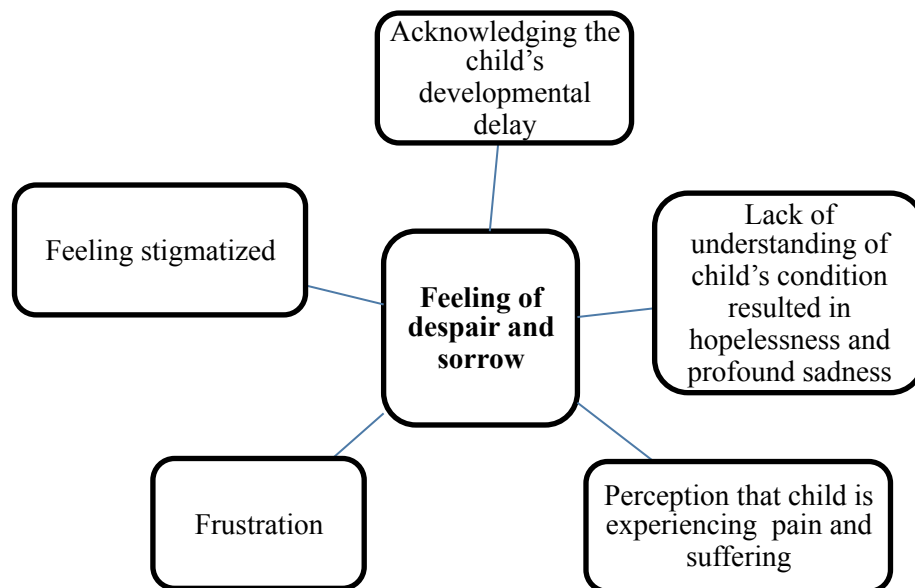
Akua also spoke of the difference it would make to her and life and her child's if he could walk:

No, my problem is if he is someone who even walks. I will be at peace with myself but he cannot walk and also, I cannot leave him alone. I always want him to be by my side until he starts walking. All I want is my son to walk for me (T4 ss 73,74).

### 4.6.3 Feelings of despair and sorrow

This section describes the final secondary theme that contributed to the main theme of ‘Developing personal beliefs to support the caregiving role’. Figure 4.3 provides an overview of the data clusters that contributed to this secondary theme and will be discussed in detail in the next sections. The participants all described the immense sorrow they felt, increasing over the years, as they came to accept the reality of their children’s condition. A number of factors that triggered the feelings of despair and sorrow were evident in the data. The caregivers described the uniqueness of the nature, intensity, and precipitating factors associated with their emotional response to the ongoing caregivers’ role.

**Figure 4.3: Contributing data clusters of secondary theme: Feelings of despair and sorrow**





#### **4.6.3.1 Acknowledging the child's developmental delay**

Delay in developmental milestones was identified as the most significant triggering factor for the feelings of despair and sorrow experienced by the participants. The caregivers frequently identified other children of the same age as the child they were caring for and, in particular, when the child had a twin who was achieving normal developmental milestones and this caused feelings of despair and hopelessness. Afua, who was a mother of three children, described comparing her other children with the child with cerebral palsy: "I feel very sad when I am dressing her younger sister to school, but there is nothing I can do about it". The constant comparison engendered feelings of hopelessness for her disabled child:

I cannot say exactly what is happening to her, all that I can say is that she is sick; she cannot sit, walk, nor talk. She is not like her sister. She is just there, and nothing can be done about her.  
(T2 ss6.)

Eno kept hoping that her son with cerebral palsy was simply going through a period of developmental delay and that he would catch up later with his twin. However, she experienced greatest sadness when she was finally convinced of the diagnosis of cerebral palsy as this removed any possibility of hope. As she explained:

Initially when the other twin was developing faster than this one, I was always hoping he will catch up later and it was just a delay. But the day that I felt really bad, was the day I was told my son was having cerebral palsy. That was at Saint Joseph Hospital, it is an orthopaedic hospital and the paediatrician was bold enough to point out that my child is suffering from cerebral palsy, and his chances of developing normal is slim, and explained the prognosis to me. That was the first time I really felt that my child is disabled and all my hopes were lost (T8 ss26).

Similarly, Akua explained that her experience had been the same as other pregnant women but the difference was startling after delivery when it became clear that: “everything was wrong with the child”. Her sadness is evident in this description of her experience:

I get hurt and I ask myself why all these things are happening to me. If anyone gets pregnant and delivers, the person delivers a very healthy baby, but when I deliver everything is wrong with the baby. With my eldest child, when I gave birth to him, he walked at the time he was supposed to walk and the time he was supposed to talk, but this one looks like he has delayed.  
(T4 ss 15, 10).

#### **4.6.3.2 Lack of understanding of child’s condition resulted in hopelessness and profound sadness**

Only one of the participants acknowledged that she was aware of the child’s condition as cerebral palsy. Health professionals appear to have found it difficult to inform the caregivers about their child’s diagnosis or to ensure that they understood the information they were being given. Eno felt that the paediatrician who informed her of the child’s condition “was bold enough to point out that my child is suffering from cerebral palsy”. The other participants described living with ‘something they didn’t understand’. Ignorance about cerebral palsy – the condition and its long-term effects - was a key factor in the despair and sorrow that participants experienced. The inability of health care providers to competently inform caregivers about their child’s condition and its consequences left participants with a deep sense of hopelessness as illustrated in the following statements:

I don't understand, but I am forced to understand, I have to understand it by force, because there is nothing I can do about it. Even the doctors are not able to tell me what is wrong with her. They always assure me that she will be well. The herbalist couldn't help. What else can I do? I have to understand that is what God has willed (T2 ss41).

I am always weeping. It is my grand Auntie who has been encouraging me to continue to pray and with time my son will be well. I don't really know what is wrong with him. But some people are just encouraging me to pray. No one has been able to tell me what is wrong with him (T10 ss 14-16).

Abena, a single parent of a four-year-old child with severe cerebral palsy, encountered similar challenges when she sent her son to the hospital: They [the health professionals in the hospital] did not explain anything to me". She further lamented:

I see that it is the sickness that is worrying him. [Health professional's question: What sickness?] I can't explain it. I see his body is weak and that is not how a child should be. So as for this one it is difficult to understand... I am always stressed ( T11 ss4)

#### **4.6.3.3. Perception that child is experiencing pain and suffering**

A recurrent concern in the participants' narratives was that their children were experiencing pain and suffering and this triggered profound sadness. For example, when reflecting on her experience as a new mother, Eno recalled the emotions of fear and anger about her child's condition she experienced:

I was in pain, enraged and angry that my child will probably not walk and he has to go through pain and discrimination as well as the time we have to spend on him, money, the insults from other people. It was just unbearable. I couldn't think of anything else to do; I was just weeping (T8 ss28b).

Similarly, Awo shared the emotions she felt when she realised that this child was the only one with cerebral palsy in her family:

One thing is that when I look at the condition of this child, I become very sad. I haven't seen anyone in my family suffering like this child, not in my father or mother's family. Therefore when I consider how she alone among all my grandchildren is having this condition, I become sad (T9 ss 13).

#### **4.6.3.4 Frustration**

The participants all expressed the deeply felt frustration they associated with their caregiver role and gave examples of situations that exacerbated their frustration, for example, being unable to understand what is wrong with their children because their children are unable to talk, pressure from people to explain what is wrong with their child, managing administration of medication, and the care recipient's attitude and behaviour. Most frequently, frustration was associated with the cognitive effort and time required to understand what was wrong with their children or what they needed. Despite the frustration, most participants developed ways of interpreting their child's needs and behaviour. As Akua stated; "Because he [her son with cerebral palsy] is not able to talk, I studied him and came up with schedules for feeding that seem to suit him". She found particularly worrying those times when she was unable to tell what is worrying her son especially when he was sick:

I feel hurt because sometimes he is sick or has stomach or headaches and I am not able to know. Sometimes when I see that he is warm, then I know that he is not well, or if it is his stomach he will be defecating frequently, then I get the message that it is a stomach upset. It is difficult because sometimes, we can give him the wrong medication if we are not careful. It is very bad if you are in such situations; it is very difficult (T4 ss 62,63,64).

Similarly, Kofi explained his difficulty in understanding what his cousin wants to communicate with him:

Her speech is not clear, when she speaks, you don't hear what she is saying unless you are close to her, or unless she uses signs before you can get her well. Sometimes you have to use your mind to determine what she is saying before you can help her... When she speaks, the other children seem to understand her better so they interpret. They are able to explain to me better (T1 ss 11,12).

Nana, a grandmother of a child with severe cerebral palsy, explained how she sometimes became frustrated when people ask her what her grandson's problem was as she did not want to discuss it particularly as people did not seem to understand. As she said:

I get frustrated, very upset, because I don't know, sometimes I just reply them [people wanting to know about what is wrong with the child] that can't they see he cannot walk, cannot talk - what else do they want me to tell them? No one seems to know what is wrong with him so I don't want to discuss it (T12 ss 22,23).

Similarly, Kofi described how he got upset when people demand an explanation of the cousin's condition:

So many people ask me about the cause of her illness but I ignore them. Even if you say it, no one will offer any help... Oh a lot of people have been asking. Some don't ask with concern, they ask annoying questions. So I don't mind such people [people asking the cause of the illness] (T1 ss 51,52).

Complying with the recommended dosage and administration of herbal preparations was experienced as frustrating because of the large quantity they were required to give their children and the bitter taste made it difficult for the child to swallow. For example, Kwaku

admitted that on occasion his frustration with this task became so great that he had physically assaulted his son. As he described:

Initially, I was getting frustrated and bored with him whenever I was giving him medication. Especially the herbal medicines that they gave him from Amen Scientific Herbal were just too much. They gave him 12 bottles of herbal preparations and it was also bitter. So he was struggling a lot whenever you wanted to give him the medication... After struggling to give him the medication, then he will throw everything up. I beat him whenever I got frustrated. But I realized that this poor child cannot talk and doesn't understand anything. I was doing that out of frustration and just wanted him to get well. I later told myself that it can't continue so I stopped giving him all the medications that he doesn't like (T3 ss 22, 25).

Another important source of frustration discussed by the participants was their child's behaviour and attitude. For example, most participants reported their children excessively crying especially in early childhood. Eno described the problem as follows:

It is because of the way he reacts when I am not around him. Sometimes it is funny, he will cry and cry until he sees me, and then suddenly he will stop crying. Sometimes when he sees that I am asleep, he will cry till I wake up and sit by him, then he will stop, meanwhile he doesn't need anything. It is just the attention. It is sometimes frustrating (T8 ss 4).

Similarly, Awo described how her granddaughter's attitude impacted on the caregiving process:

If you refuse to attend to her, she will cry very loudly till you stop whatever you were doing and attend to her, before she will stop. I sometimes get annoyed but what can you do, you have to attend to her. You have to be patient and care for her (T9 ss 11).

#### **4.6.3.5. Feeling Stigmatized**

Other data revealed the participants', who were biological mothers, sense of humiliation and personal failure for having given birth to a child with cerebral palsy. Feeling ashamed of one's situation after the child's birth was a commonly raised issue. These participants talked about their feelings of anticipation and pleasure during the pregnancy at the delivery of a healthy child. The reality of their disabled child's birth generated feelings of guilt associated with the potential causes of their child's disability. Firstly, they felt guilty for disgracing their families by delivering a child with cerebral palsy. Secondly, they attributed the child's disability as a spiritual condition associated with their family. Thirdly, they felt it was punishment for a sin they have committed against God. During the interviews, participants revisited the feelings of guilt and shame they experienced about having a child with disability immediately after childbirth and in early childhood. Most of these participants attributed the cause of their children's condition to something about them or something they had done. For example, when reflecting on her experiences as a new mother and a health professional, Eno recalled the conflicting emotions she felt on delivering a child with disability and during the first year. As she said:

I cried a lot; in fact I wept so much because of how first of all it was going to affect my profession as a health professional. People look up to me, and they will criticise me that I have been helping people to deliver normal babies and I had delivered a disabled child. That day I felt really bad, secondly I was thinking that I have brought disgrace to my family (T8ss28a).

In her mind, as a health professional assisting women to deliver normal babies, she should have set a good example by delivering a healthy baby herself. Alternatively, Kwaku felt his son's condition was caused by sins he was guilty of committing. As he said: "I will not

deceive you, from the beginning I was shaking, I kept on thinking, ‘what sin have I committed?’” Similarly, Akua felt that she has caused her son’s condition because she did not eat good food when she was pregnant:

Yes sometimes [feelings of guilt]: I could not provide the strength that my child should have received when I was pregnant. [Question: Why do you blame yourself?] May eating anything I get just to fill the stomach, might have caused his condition (T4 ss3)

Akosua attributed her son’s condition to an evil person from her family [specifically her grandmother] wishing to do harm to her son and causing her son’s condition. As she said:

Maybe the evil one is in my family. I have a grandmother who I think might be the one doing that. They are many reasons, when this grandmother sends me I don’t normally go maybe that was why she did that to my son (T10 ss 5).

The participants internalised these feelings of blame and guilt and then anticipated that others would also attribute blame to them and that this, in turn, would affect their relationships with family and community members. As a result, participants were concerned about revealing and identifying their child’s disability and were afraid that they and the child would be marginalized or discriminated against. Adwoa isolated herself from the public in order to hide her son for fear of people harming him: “Sometimes I tell God that he should allow me to be able to mingle with people”...Someone might even poison her. They think she is not a human being and should not live”. Eno was similarly concerned about people visiting her at home and she stopped working as a health professional for eight months to prevent people from identifying her child’s disability. As she said:



At first he couldn't see, he had cataract which was removed for him just recently. He was always by my side, I didn't want anyone to get closer to him so he was always by my side. I didn't want people to see that he was blind. They will start spreading the information that he can't also see. Because of that I spent almost eight months in the house taking care of him and preventing people from coming closer, till he had the surgery and the cataract was removed (T8 ss 42, 44).

#### **4.6.4 Summary of section**

Caregivers developed religious and spiritual beliefs to support the caregiving process. The development of the beliefs and perceptions resulted into mixed feelings. Positively they perceived that their child's condition was from God so they were committed to caring, coping, had hope for the future. The caregivers also described their understanding and perception of cerebral palsy and developed their estimation of recovery. They attributed the cause of cerebral palsy to spiritual origin and hence sort for spiritual intervention. Negatively caregivers described the triggering factors of feeling of despair and sorrow as frustration, lack of understanding of the condition, felt stigmatised and perceived that the child was going through pain and suffering.

#### **4.7 Main Theme 2: The demands that shape the experience of caring**

The second main theme represents the actual burden of caring for a child with cerebral palsy and the diversity of demands that shape the reality of caregiving. In the subsequent sections the participants' perception of the effort demanded to successfully care

for their children and provide their basic needs is discussed in detail. Eno's description of her experience of caregiving captures the holistic, all- consuming nature of the role:

Caring for a child with cerebral palsy has not been easy at all. As a young mother who had not given birth before and to go through all these stressful situations - apart from the financial demands, the stress of keeping late at night, changing diapers, sometimes you feed him and the food will be coming out from the nose, very scared of being at risk of choking, cleaning up, sometimes he becoming aggressive - all those things, it hasn't been easy (T8 ss 21).

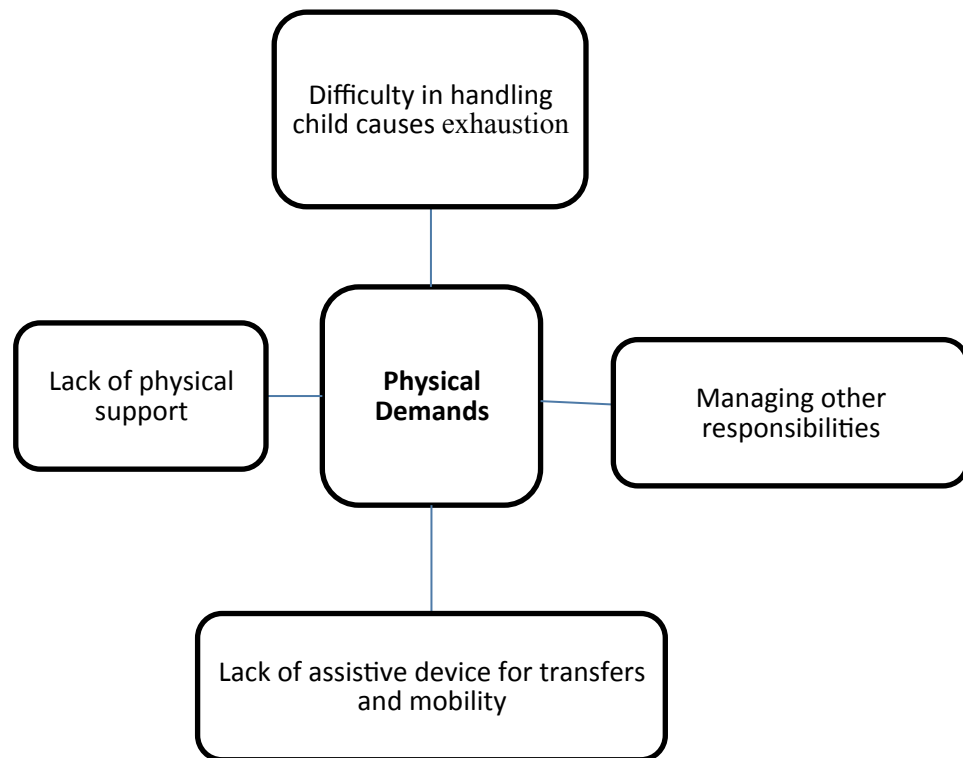
The participants experienced caring as; "suffering", "hardship", "tiring", "unbearable", "difficult" and "sacrificing" and their descriptions of the effort involved in caring for their children were closely linked to the health of their children. The following secondary themes contributed to this main theme:

- Physical demands
- Financial demands
- Societal influence

#### **4.7.1 Physical demands**

This section presents the first secondary theme that contributed to the main theme of 'the demands that shape the experience of caring'. Children with cerebral palsy experience marked activity limitations; hence the caregivers are responsible for assisting their children with activities of daily living. These responsibilities impose considerable physical demands on caregivers, which all the participants identified. Figure 4.4 provides an overview of the primary data clusters that contributed to the secondary theme of physical demands.

**Figure 4.4 Contributing data cluster of secondary theme: Physical Demands**



#### **4.7.1.1 Difficulty in handling child causes exhaustion**

The participants identified and agreed that proper handling techniques could have eased the physical fatigue they experienced as a result of caring for their children. They all faced increasingly difficult challenges in handling their children as they grew in height and weight and these challenges were compounded by the neurological and musculoskeletal complications associated with cerebral palsy. Spasticity, commonly described by the participants' as "stretches the body and she becomes stiff" was the most significant complication they described as the cause of their inability to handle their children. Caregivers identified some of the activities they found most difficult as handling their children during bathing, changing diapers and soiled linen: "Bathing is not an easy task

and takes time”. Afua gave this description of her current and worsening problems in physically handling her 13-year old daughter:

Sometimes she will soil herself with urine and faeces, so I have to get her clean. It is not easy She is now heavy and tall, to handle her during bathing time is not an easy task. I sometimes struggle with her for more than one hour trying to clean her. She will not be calm she often stretches the body and she becomes stiff. No amount of strength can handle her. I become very tired (T2 ss17).

Akua’s experiences of bathing her son were further complicated because her son could not stand which prevented her from bathing him near the gutter where the water drained. As a result, she had to fetch water every day because she had to use the same basin to fetch water and bath her son. As she explained:

You see I like to fill all the basins and buckets in the house so that I do not have to go and fetch water every day. If he [the son] was ‘an abled-bodied child’ he would just stand by the gutter for me to bath him. Here is the situation I have to put him in a basin before I can bath him. If I hold him with two hands I cannot bath him so sometimes I have to put him on the floor and bath him because he is very heavy (T4 ss 75,76).

Adwoa shared her concerns about her child falling during bathing in a basin or bowl if she was not sufficiently vigilant:

Initially, I used to place her on my lap but because she is growing, I put her in a bowl then I hold her to bath her. Sometimes when she becomes happy she will fall out of the bowl, so I have to always be alert. I have watched her so many times she gets up in the bowl so I hold her (T5 ss 26,27).

Considerable strength is required to bath children with cerebral palsy and the problems, particularly experienced by women, are illustrated in Mena’s comment:

Sometimes when I am bathing her, she would be struggling with me. She's now stronger than me. If she's doing something and I tell her not to do it, she can struggle with me till we all fall down (T7 ss40).

Feeding their children was perceived as a 'full time job' by most of the participants. Awo explained: "In feeding my child, finances come into it, you have to get money to buy the food, and you need strength to cook it and time to feed the person till the they are satisfied". Participants also raised the issues of food texture, procedure, frequency, and preparation associated with feeding and how long it had taken them to master these skills.

As Adwoa described:

It is difficult to feed her solid food, you can spend like two hours to feed her solid food since she cannot swallow quickly. She is not able to eat well. When you feed her, she will bring the food out again, unless you put your hand in her mouth (T5 ss 11, 12).

Similarly, Afua described having to mash a portion of what she herself eats to make it soft for her child. As she said: "She only eats soft food. She cannot chew, so I normally make a portion of what we eat soft or mash it for her" (T2 ss40). It became more complicated for

Eno as she has twin:

The process of feeding is not easy at all. At times I have to go to work, that was when the major problems started. I have to leave them with my Nanny and it was difficult for one person to care for both children. Although one was able to walk, the other one was not able to do anything (T8 ss 20).

Kwaku's described his son as difficult to feed and he was the only one in the family who could manage and if he was not there his son did not get fed:

His feeding is very difficult. Sometimes you don't even know how to handle him. On few occasions he becomes calm for you to feed him. So if I am not there it becomes very difficult for my wife or any other person to feed him. You know he is tall and strong. He is sometimes very stiff (T3 ss20).

The participants stressed the relentless nature of feeding their children as it was repeated at least three times a day and throughout the years. For example, Akua explained the schedule saying: "I give him the kooko [maize porridge] at 9 am then again around 12 pm. Sometimes when I get fruits like banana and oranges, then I give him some in the afternoon around 1 pm, and then around 4.30 pm I give him any other food we have in the house".

#### **4.7.1.2 Managing other responsibilities**

All the participants identified a diversity of other responsibilities and tasks that required physical energy and effort. Although most of the caregivers were unemployed, they did have other responsibilities they were required to perform in addition to caring for the child with disability. These included going to work, caring for other children, farming, fetching water and hand washing of clothes. For example, Afua summarized her daily routine and responsibilities as:

What I have been doing is that I wake up very early every morning and start to prepare the things that I have been selling. I then go and help her younger sister ready for school. When the sister goes to school then I clean her [child with cerebral palsy] (T2 ss16).

Eno also explained that she had to cook for the family at night and Kwaku experienced sleep deprivation during the night:

Sometimes he doesn't want to sleep at night. You have to wait with him as late as 1 a.m. before he will sleep for you to also sleep... These boys, they can eat throughout the night. Sometimes I will be wearing my underwear and I will be in the kitchen preparing porridge. This one [the child with cerebral palsy] too was a crying type; he will be crying and crying (Eno, T8 ss 6, 33).

Normally my son doesn't sleep during the night he will be making noise till about 1 a.m. I don't even understand what he will be saying, as if he is playing with someone. So sometimes he disturbs me throughout the night (Kwaku, T3 ss 3)

Most participants were unable to participate in a social life or social roles because of the demands of caregiving. As Awo explained:

Her parents are both teachers so because of their work schedule, I don't want to disturb them, I want them to concentrate on their work. I can't just go and dump this child on them to go for funerals or other events. Sometimes I have to ask someone to take care of her [the granddaughter] briefly so that I can rush to our family house. That is something that worries me a lot. So if something should happen in my family, sometimes I am not able to go at the time and day I would be expected to be there. On rare occasions, I go and leave them with her parents over the weekend to be able to attend to important family calls (T9 ss 16).

#### **4.7.1.3 Lack of assistive device for transfers and mobility**

The participants discussed how important it was that they maintain their physical strength in order to carry and transfer their children on a daily basis and continue to do so as they grow. They all felt that this was the key to their success as a caregiver. None of the female participants mentioned having any assistive devices or equipment that could help them lift, transfer or move their child around. They also recognised that the presence of stiffness [spasticity] increased the loss of movement in their child's joints [contractures]

and made transporting and carrying the children extremely difficult. Their ability to carry the child enabled them to go outside the home to work or market. For example, Afua was unable to carry her daughter and experienced her inability to leave the home with her child as a worry and hardship. As she explained:

I still care for her just like a baby though she is now big, heavy, and tall. At first I used to carry her on my back to wherever I went but now I'm unable to. So I don't go anywhere. It has really been hard, I am not able to leave her alone in the house, even if I do, or leave her with someone I have to make sure I come back as soon as possible. She is heavy and I cannot carry her on my back. Because of this I rarely go out, that is my main worry (T2 ss11).

Similarly, Esi was concerned that she could no longer carry her child to school as she used to do when she was younger. Her child growing and increasing contracture development compounded her problems, as she explained:

Her walking is the problem. Now before you can carry her out, it's very difficult. I used to manage to carry her to school. What can help me to take her to school is my problem now...She can walk up to that house. As you can see, when I put her on the chair, she coils her legs, so I have to help her before she could stretch them (T6 ss 32).

Akosua had two young children and was unable to carry both on her back to go and sell in the market, which was her sole means of making money. As a result she had to depend on her brother and wife for money and food. As she said:

I used to go to the market with her but since I delivered my second child and Harrison is too far for me to walk, I can't carry the two children at my back. I remain in the house and my brother and his wife go to work and come back with a little something for me and my children (T10 ss34).



Several participants described how the lack of appropriate equipment meant they had to adapt things for their children to sit in, for example, old car seats and how dangerous this was in terms of being uncomfortable for the children, causing bad posture and sometimes the children fell out and hurt themselves. As Afua said: “I used to put her in an old car seat and bring her outside, but she is now old and she would not sit in the seat quietly, she will stretch herself and she will be on the floor” (T2 ss13) and Kwaku described a distressing experience: “One day he was sitting in the old car seat, and as soon as he saw us coming from the gate, he jumped from the seat and fell on the ground and had a cut on the mouth, it was a deep cut, I think I even took a picture of it, he had a deep cut” (T3 ss27).

#### **4.7.1.4. Lack of physical support**

Most of the participants reported that they did not have other people to support them in caring for their children. For example, Akua explained that when she left her two children with her in-laws, they in turn left the son, who has cerebral palsy, with his sister who at the time was only seven years old because they had to work on the farm. As she explained:

I felt bad because the elder one who is seven years could not continue her education and because their grandparents were farmers, they leave him with her sister and go to the farm...Whenever I call and they [in-laws] will tell me that they were still on the farm and later when I am able to talk to my daughter, she will complain of hunger, and sometimes she will say she is preparing food and cleaning her brother and that was very disturbing (T4 ss 51, 52).

Similarly, Kwaku explained that he had no one to stay with his son with when he had to leave to seek work: “He is sometimes very stiff. I am even thinking of going to look for another job, but whom am I going to leave him with?” In contrast, Afua’s mother was available to keep her daughter company but she was old and unable to physically manage the child. Afua said:

The only problem is that my mother is old and she is not able to lift her up or change her diapers. She [the child] cannot lie down quietly; she is always throwing her hand and legs. Her movements have been discouraging me from leaving her with my mother (T2 ss 25b).

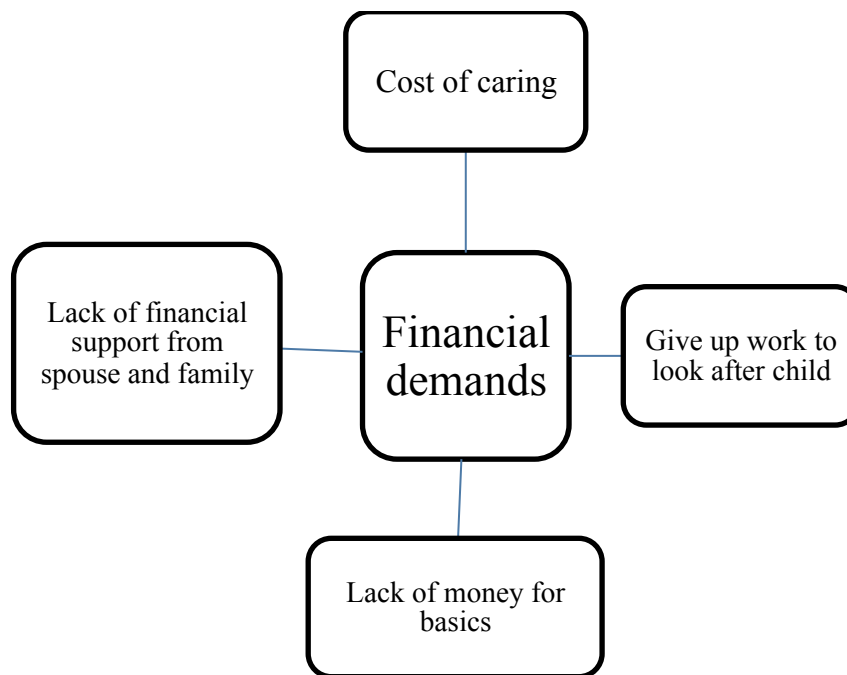
The physical demands of caring for a child with cerebral palsy had a negative impact on the health of all the participants. Most experienced musculoskeletal pain as a result of continually lifting and carrying their children and none of the participants had anyone with whom they could share these responsibilities. As Adwoa said: “As she [her daughter] is growing, she is becoming heavy so if you want to carry her, you feel the pain in your arms and waist (T5 ss 19).

#### **4.7.2 Financial demands**

This section describes the second secondary theme that contributed to the main theme ‘the demands that shape the experience of caring’. For all the participants, caring for a child with cerebral palsy was an ongoing financial strain. They all acknowledged that all families in rural Ghana were experiencing ‘economic hardship’ regardless of whether they had a child with disability or not. However, caring for a child with cerebral palsy significantly added to their financial difficulties and most of the participants lived in poor

and miserable conditions at the time of the interviews. Expressions like ‘having no money’ and ‘financially it had not been easy’ were common threads in their narratives. Figure 4.5 presents the data clusters that contributed to this secondary theme and reflect the pervasive nature of their financial concerns

**Figure 4.5 Contributing data cluster of secondary theme: Financial demands**



#### **4.7.2.1 Cost of caring**

The participants perceived that they spent most of their limited financial resources on interventions that they hoped would improve the child’s condition or result in their complete recovery. Only one participant indicated that she spent money on orthodox medications prescribed by health professionals. Most of their resources were used for spiritual interventions and herbal preparations that, in reality, did not improve the child’s condition or quality of life. In addition to paying for such interventions, the participants

also discussed the extra money necessary to transport their children to the appointments with herbalists and spiritual advisors. Transportation often presented a problem as the children were physically fragile and frequently became aggressive on public transport meaning that they had to hire a car or taxi. Eno spoke of how she bought different kinds of medications in her efforts “to seek for any drug that could heal him” even though none were effective. She explained the burden involved in getting medications for her child:

Financially it was a lot. When they realized that he was having cerebral palsy, they have to put him on medication, I remember in Koforidua [name of a city] they started him on a drug which was about 12 cedis (3 dollars) at that time. We have to buy it for 3 months, and each week we were using one bottle, after that we have to send him back to the hospital for them to prescribe another one. Later on, one of the physician assistants also prescribed another drug for him, that one was expensive as 150 cedis (35 dollars) to be taken within two weeks. We had no other choice than to buy it for him, we were just seeking for any drug that can heal him. This person will say buy this one, another will also say that one, blood tonics and others so a lot of money was used but none was effective (T8 ss7).

Several participants detailed the different items they had to buy to support spiritual interventions. Kwaku said: “Each of them (spiritualist, traditionalist, and herbalist) asked for money and certain items so that they can deliver my son from his condition. Some asked for a goat or a sheep, white handkerchiefs and the rest, but none of them could help”. Akosua explained the stress caused by trying to find the money to follow the recommendations of people and feeling as if she had failed her child:

At first my grand auntie showed me some herbs and I bought them from the market. That one I used as an enema, I did it several times but I did not see any improvement. Someone else said I should send him to a prayer camp. I paid 500 cedis (125 dollars). They did all that they could but there was no improvement. Currently I don’t have

any money so I am not going to send him anywhere again. I don't have money to be sending him for prayer meetings (T10 ss 18, 20).

The 'cost of caring' data cluster overlaps with the data cluster 'strategies to improve the child's condition' connected to the secondary theme 'perceived standards of care' described above. Although the two data clusters clearly have a separate focus, finding ways of helping their children against all odds meant significant personal financial difficulty for the participants, an experience they all shared. In most of the interviews the participants described continuing to pursue possible costly remedies even when these interventions were obviously not effective. These sacrifices are evidence of the participants' concerns for their children and their future.

#### **4.7.2.2. Give up work to look after child**

The seven participants who were not employed all expressed their desire to work and to have an income but all had given up employment opportunities, regardless of their relationship with the child, in order to care for them. Awo, being a grandmother, chose to give up her bakery business as she found it impossible to combine work and her caregiving responsibilities. This decision was further complicated by the death of the person who assisted her in the business. As she explained:

Caring for a child with this condition is tiring. I was a baker but I am no more in the business because of this child. The one who was also assisting me to bake also died a year ago. I employed another person to come and assist, but he couldn't manage the finances well. Now I am out of business because I am looking after my granddaughter. By this time, I should be at the roadside to sell, but she may need something and I have to do it for her (T9 ss3).

Similarly, Akua used her limited extra time to sew dresses but she had to stop work because people did not pay for her services. As she said:

Caring for him has prevented me from working. Even now I have stopped the sewing because the area in which I live, the people do not have money to pay for the service. After using the little time I get to sew the things, they don't even come to collect it. I cannot leave the children to go round to look for them...I am just hoping that when he starts walking, things will be fine but it is really difficult (T4 ss7).

For other participants the reality of 'economic hardship' meant that they somehow managed to combine caregiving with generating some income. For example, Afua described how she managed:

Currently because of the economic hardship, one becomes poor if she or he stays at home. For the past thirteen years since I gave birth to the twins, I have not been in any gainful employment. Instead I do some petty trading in front of my house. I normally keep her [the child] inside and I will be outside selling what I can (T2 ss 12).

These decisions to combine the responsibilities of making a living and caring for their children were difficult and stressful for the participants. Afua, for example, during the interview was clearly very worried that she was not able to devote all her time to caring for her daughter and she was determined to stop trading if she found some other source of financial assistance. Eno also discussed the difficulties she experienced and the personal sacrifices she made in maintaining her employment and caring for her child.

It [child's condition] has affected my career in so many ways. Last year for example, I had to postpone my education [continuing professional education] because of his situation. Sometimes, even leaving him in the house is a problem. He seems he doesn't like anyone and he doesn't want to go near anyone even those that he is

close with. It is extremely difficulty to leave him in the house (T8 ss 3).

#### **4.7.2.3. Lack of money for basics**

The consequences for the participants of not being able to work and make an income were diverse but all had a negative effect on their lives and their child's and created considerable personal stress. Lack of money to provide basic needs for themselves, the child and other family members was the predominant concern. Many of the participants depended on occasional charity from friends and other family members. For example, Adwoa who was single and unemployed, said: "my friends will give the children some money and that is what we manage on". The participants experienced considerable emotional stress when they were unable to provide their children with the basic needs, such as, food. For example, Kofi described how frantic he felt when he realised that his cousin [who he cares for] was hungry and there was no money to buy food for her. In his view non-disabled children could work and fend for themselves but his cousin could not and required him to provide for her and he was failing in that duty. As he said:

When I have nothing on me, I mean money and I find out she is hungry, it worries me. As for the rest of my children, they can work to fend for themselves but this one is unable to work...As for me, I have taken her as mine so if she needs something, I accept and try my best to get it for her. Now it is money that I don't have which worries me for her, but no other thing in particular...I have taken her as a sick person, and if she requests for something that demands money and I am not in the position to provide it, it worries me. I wish I could fulfil her requests immediately (T1 ss 31, 17).

Adwoa described how, when she has no money, she prayed over the water to replace the milk she could not afford to buy and fed her child the same food every day for two weeks:

Financially it has not been easy for me. Money to buy food with is always a problem...For example, I used to give her baby milk around 5 a.m. but because there is no money now, I fetch water and pray over it and give it to her. If she drinks then early around 7a.m, I cook for her...Food like akple (boiled dough prepared from maize), I cook it very soft with palm nut soup. Then, around 12 p.m, I feed her the same thing again, around 4 p.m. too. I feed her till she sleeps with the same food (T5 ss 15, 16, 17, 22).

Another problem, related to lack of money, for the participants was their inability to pay their main bills, for example, electricity and rent. Esi gave an example that reflected the ordeal and stress that participants regularly experienced:

She [the child with cerebral palsy] is always in the room. When we used to have electricity the television is always on and she watches cartoons. She likes watching cartoons. But because I don't have money to pay the bill, they have disconnected the lights in this house, so now when we are not at home she is just in the room alone sleeping. But to keep the bill paid I have to the market - maybe at 6:30 pm or 7pm... Sometimes in the afternoon, I come home to attend to her then I go back to the market leaving her alone (T6 ss33).

The participants also identified how lack of money made accessing basic health care difficult or impossible. For example, Akua had to borrow money to renew her child's health insurance card before she could send her sick child to the hospital: "I borrowed money from someone and went for the picture to do the insurance for the child before I could take him to the hospital". Kwaku, because of lack of funds, was not able to take his child to the hospital when he fell and sustained a deep cut on the mouth. He described how he managed in this situation:

We didn't know what to do with him, I know when we send him to hospital we will be asked to pay money, and we had then used all our money to buy food and other items. We didn't have a pesewa



on us... I then heard a voice that I should send him to the room, so I did. I then clean all the blood, then I prayed for him and applied shear butter, it became big. The whole mouth got swollen, but we continued praying to God. It has healed neatly, as if the cut was sutured. It is by the grace of God (T3 ss 27, 28).

Abena provided another example of the consequences of not having money for health care. She described how her son, who had severe malaria, was discharged prematurely from the hospital because she was not able to buy the medications and the father did not provide any child care support:

He [her child with cerebral palsy] had malaria and I took him to the hospital. I didn't have any money. It was so serious that he was admitted and I couldn't buy the drug that was prescribed for him. I wept very bitterly because I thought he would die. I went to his father to inform him of the situation but he barred me from his house. He said he doesn't care about the child anymore, and the child can die, he couldn't care less. I wept and wept. I came back to the hospital to inform the nurses, but they said if I'm not able to buy the drugs, then there is no need to keep him in the hospital. She just gave me one medicine and we were discharged. Later it was one of my grand aunties who prepared some herbs for him and he got better (T11 ss 36).

#### **4.7.2.4 Lack of financial support from spouse and family**

The lack of support from spouses and family members were issues raised by most of the participants and often lead to them wishing to give their children up. For example, Akosua expressed her desire to give her child to an orphanage because she had no money or source of income and no support from the fathers of her two children. As she said:

There is no one to help me and I don't have any money. I had to stop work when I got pregnant. Since then caring for the two children has been very difficult. That is why I have been saying that if I could get an orphanage, which would accept him, I will give

him up. I am exhausted. I don't know why all these things are happening to me. I don't have anyone to help (T10 ss 8).

Most of the participants provided examples of the children's fathers being absent and abandoning them both in terms of emotional, practical and financial support. Kofi became the caregiver of his cousin, who has cerebral palsy, after her biological mother died and the father, who he described as 'senseless and insane' had disappeared. He hoped that one day he would return and accept his responsibilities for his daughter, specifically when the other daughter married as this was an occasion when fathers are acknowledged and honoured, but meanwhile he struggled to manage caring for both his cousins. As he explained:

Her father is alive. Since their mother died he left Adumajan to go to Akosombo [names of towns], he has not returned yet and he does not look after them. I learnt he is fishing in Yeji [name of a village] and has not returned. I consider him as senseless and insane. I am just waiting to see if his next girl grows up and gets married, I want to see if he will come and claim she is his child or not (T1 ss 27).

Several of the participants described how the fathers of their children left when they learned their child had a disability. In some cases, the fathers left and did not return because they were not working or had to go away to find work. As Esi explained: "He [her husband] is a man and he is far away from us. Because he is far away he can't help. If he gets money he gives and if he doesn't, he stays there. He can't see or feel what we are going through here". Afua described a similar situation:

He [the child's father] does not stay with us, he stays somewhere else and he hardly visits. He said he has no money to give us because he is not working. He was with us when we were all looking for a cure for our daughter, but he got tired and left us. He does not support in any way. I do everything (T 2 ss 26).

Abena, a single parent, indicated that the father of their son does not communicate with her and blames her for delivering a child with cerebral palsy when there had been no other such children in his family. As she said:

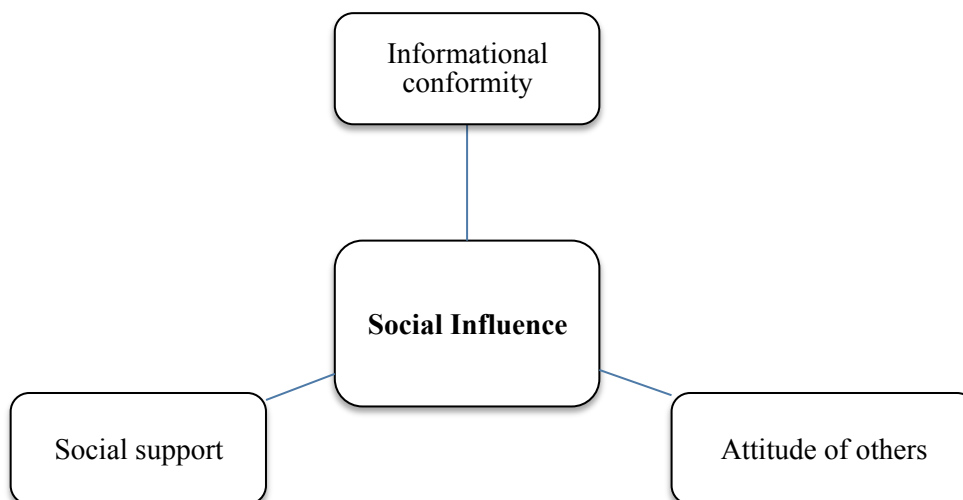
He is not talking to me. I don't know where he is. When we realized that our child couldn't sit nor walk at the age of 9 months, he left saying that they don't have disabled children in their family so our child does not belong to his family. So he left, I have not been seeing him (T11 ss 2).

#### **4.7.3 Social influence**

This section describes the final secondary theme that contributed to the main theme 'The demands that shape the experience of caring'. The influence of the participants' social context, in terms of demands made by individuals in the community and the need to conform to society's expectations, were evident in the participants' narratives. The participants frequently complied with recommendations made by members of their community and frequently acted on it without evidence of veracity or effectiveness. This acceptance was reflected in words like 'they said', 'people are saying' and 'people will say' and shaped the participants' accounts of taking care of children with cerebral palsy. The participants acknowledged how their society influenced their efforts to find interventions to help their children and make decisions on their behalf. They frequently identified how society's expectations and attitudes conflicted with their own personal beliefs and values. This conflict caused considerable emotional distress particularly as they often agreed with, and acted on, suggestions from others particularly family members but privately disagreed with them. As Afua said: "I don't say anything [faced with negative

advice], I just respond okay. But I don't follow it." The data clusters that contribute to the secondary theme of social influence are summarised in Figure 4.6

**Figure 4.6 Contributing data cluster of secondary theme: social influence**



#### **4.7.3.1 Informational conformity**

The participants described many instances in which they conformed or yielded to a community position or relatives' opinion or attitude against their own 'better nature' or opinion. They explained that they made these decisions to conform in order to align themselves with their society's roles, norms and expectations and to maintain their identity within the community despite the fact that the suggestions and opinions offered them were often not positive. Frequently, others labelled their children with cerebral palsy as animals like lizards, snake monkeys, or special beings like river children and dwarfs and the participants admitted that because "we don't know exactly what is wrong with them, we believe whatever people say". Afua described opinions others shared with her:

They just say that she is an agama lizard. Just like how the lizards change colours. At first her urine was dark brown like blood and she keeps on changing. She has also been throwing her hands and legs around like a lizard...They have given me so many suggestions. Some of them tell me that she is a river child so I should have allowed her to be sent away. Some of them also say that I should keep her till God calls her (T2 ss7, 34)

Some participants were aware that uncritically acceding to others' opinions was detrimental to them and their children. As one participant said: "If you are not careful you will not have any meaningful life. All your life will be do's and don'ts from others".

Participants also spoke about positive advice and suggestions they were given that they found useful, including that God gave them their children and, therefore, they would have a good future and that they should care for them. These positive aspects of information conformity focused primarily on support for their religious and spiritual beliefs and these have been included and comprehensively discussed in relation to Theme 1: Developing a personal belief to support the caregiving role. The participants also represented the advice they were given, about possible resources to support improving their child's life or aiding recovery, as largely positive even though the resulting interventions were rarely effective. In conforming to the advice given, caregivers found themselves resorting to 'healer shopping'. As Kofi said: "Anytime anybody who claims to have solution for her sickness comes around, we send her [the child] to see if they could do something about her condition". The participants also indicated that they developed an interest and confidence in recommended medications if someone else testified to their effectiveness. As Kwaku said: "I have been hearing testimonies from others who have been using the anointing water and it had worked for them. Some had instant healing and others get it gradually over some years". Afua continues to search for a cure for her child

even after thirteen years but without success. She described her latest attempt based on advice given by a member of her community:

She is now thirteen years old, I am still looking for a cure. Any medicine that anyone will introduce to me I will give it to her... We were moving from one place to another seeking for a cure but it was not yielded any result. When she was nine years old, her father sent us to see herbalist who gave us some herbs to bath her. That was when we started seeing some improvement. She was very floppy but after bathing her with the herbs her muscles were becoming a bit stronger. She was now becoming stiffer, not floppy as she used to be. We were introduced to a female herbalist who had been curing children who behaved like lizards. She bathed her with herbs and gave her some that caused her to vomit. The herbalist explains that she has mucus in her throat which is preventing her to talk. But it did not work. At the time we were receiving treatment, there was another woman who also brought her daughter with similar problems. She got better while my child's own was getting worse. So I got to know that the girl's sickness was different. After that place I did not send her to any place again (T2 ss, 1, 5).

Despite having reservations most of the participants complied with the recommended intervention protocols and advice, always with the hope that, on this occasion, the treatment would work. Kwaku described how he complied in this way:

We started taking him to Kumasi when he was six months old. He was two years old when we sent him to a homoeopathy clinic, we went there till he was four years, and we were going there monthly. We never missed any of our appointments (T3 ss 6).

Similarly, Akosua complied with all the treatment protocols and paid for them before she realized that it was having no effect: As she explained:

At first my grand auntie showed me some herbs and I bought them from the market. That one I used it as enema, I did it several times but I did not see any improvement. Someone else also said I should send him to a prayer camp. I paid 5 million old cedis (120 dollars) ...the pastors' boiled hot water and

they put some holy water to mix it to become warm and they will put him (the child with cerebral palsy) inside. That was all that they did for him. It was not working so I stopped (T10 ss 17-21).

Mena shared her sad experience of witnessing her daughter drinking “dwarf concoction” which could have caused severe morbidity or even the death of her daughter:

So when people were complaining, they said that, maybe it’s a dwarf, so they went for dwarf medicine. They said if they use it and bath her, she will go back. They did exactly that and nothing happened...She was about six years old (Question: how did you feel?). I gave everything to God. I said God will protect her (T7 ss 16, 34).

The least positive suggestions that participants received focused on ending the life of the child with cerebral palsy. For example, Adwoa described: “People try to discourage you: some will tell you to poison the child, others will tell you to go and abandon her somewhere and some even advice that we dig a pit and bury her” (T5 ss 6).

Participants described feeling frustrated and confused by information they were offered that was based on a diversity of religious sources and beliefs. This often meant they complied with a belief system in conflict with their own. As Ama described:

I am a Catholic and that is our belief, but people were bringing certain beliefs that are not Christian. They asked me to go and call the spirit to ask them [her twins] what they want. There were so many issues about this belief... It was a great conflict. As a Christian there are so many things I actually don’t believe in, so many beliefs are associated with twin delivery, that they are special and so on. They are restricted from eating some foods etc. The places they have to go and not, but I am also a Christian and I have a different belief, so that made life very stressful for me (T8 ss 11 and 12).

The participants found it particularly difficult to reject or not fully comply with directives from influential people like parents, spouses or religious leaders. For example, Eno felt it was impossible to disobey her parents:

Sometimes what made it more stressful is when it is between you and your biological parent, like it looks like you are disobeying them. Being a nurse I understand that it is cerebral palsy, and I don't follow what they are saying about my child. Because of that, they were accusing me that it is my fault that the child is suffering because I don't comply with treatments they proposed and I have been doing my own thing. She also said we modern mothers don't listen to advice from adults. They are more experienced than we are (T8 ss 13).

Eno's situation was compounded when her husband agreed with her parents proposed treatments. However, as a health professional, she was able to access professional advice and information. As she said:

My husband is not a strong Christian, it was a sort of conflict between my husband and me because he was agreeing with my parents that we should go and perform the rites. But I insisted because it did not make any sense to me. It was some sort of conflict but later on when we were going to the hospital, he understood the condition better (T8 ss16).

Esi did not have access to professional assistance and was unable to change her husband's opinions about his child. She poignantly described the situation:

She [her daughter] can't hold her neck or do anything. She was just like a rock and people said she is a spirit child... It was my husband who came to tell me that they said I should bring her home to be treated locally, but I said no. I was disturbed with this suggestion...He wasn't angry but he said something and I wasn't happy. Anytime I remember, I grow angry and even weep. He came to tell me that in his family, no one has ever given birth to a child like this, so what I've given him is a curse (T6 ss36).



Some of the participants' communities considered the delivery of twins as auspicious, that they were special, and brought blessings on the parents. Therefore, the failure of one of the twins to develop was unexpected and disturbing. As Eno described:

When my child was young and he couldn't open the hand, my mum claimed he had something in the hand that he wants to give to the parents so that they become rich. In my family they have many superstitions about twins' delivery (T8 ss 9,10).

However, attitudes towards the twin with a disability changed. As Eno said: "At first they think twins are special so we have to worship them. In a case where a twin is disabled, then they think it is a curse" and that "the first twin had offended the second twin that is why he is sick. They also believe that it is only the first twin that can make the second twin well". Afua, influenced by community beliefs, did not allow her daughter with a disability to see her twin sister because she might also develop the same condition:

My family think the twin might also be sick if she is allowed to interact with her twin sister. There are many superstitions about twins. They believe that once one is sick there is the likelihood that the other one too will be sick (T2 ss 20, 22).

#### **4.7.3.2 Attitudes of others**

Adwoa's comment "children like this do not need to be brought to where people gather" reflects the discriminatory attitudes held by society towards caregivers and their children with cerebral palsy and this topic was discussed by all the participants. They gave a number of examples of how these attitudes lead community members to behave negatively in the presence of them and their children. Adwoa described how:

Initially, I used to carry her around to sell where we used to live before, but they refused to buy from me when they saw her. It even brought some quarrel between me and some adults; they said children like this do not need to be brought to where people gather and I asked whether the child is not human, and is it not the same blood that flows in their body that flows in the child's body? So I stopped selling there ever since (T5 ss 30).

Adwoa also experienced discrimination at the nursery school where she worked as a class attendant. As a condition of her contract she had to reside on the school premises with colleagues but she had to resign because the head teacher was concerned that Adwoa's child was not achieving normal developmental milestones. Adwoa described the situation as follows:

The madam told me my child is not fully human so I should stop working...I was actually living there; she also said the child is not growing well. I told her I have heard her and left because she owns the school...my child was about 8 months old...It was because of the saliva that was always coming from her mouth (T5 ss 44-47).

In addition to the lack of support by fathers, participants also identified that the negative attitude towards children with disability was a problem for them. Akua's situation provides an example, she explained:

When I was pregnant with the first child the father said he wanted a boy and I gave birth to a girl so he was not coming around for some time...He [the father] was happy, he accepted the child when he was told that I had delivered a boy, but when the baby started falling sick and he was told about his condition, he started drawing back. So gradually when he realized that the child could not walk, he withdrew completely (T4 ss 48).

Similarly, Eno described her husband as "being at the denial stage, it is not easy for him," when she gave birth to twins and found his attitude difficult to understand:

The father likes the other twin because he sees him to be normal and intelligent, I don't blame him, he thinks the other twin has a lower IQ, and he is also disabled, he doesn't know that some children with disability have higher IQ than normal children (T8 ss 53).

An issue of concern, some of the participants raised, was the attitude of non-disabled children towards the child with a disability. Esi described this problem as:

Actually, some of the children do not like to going close to her. It's not all of them who go close to her..... It's because of her condition .....I can't best tell, but because of the condition, they think she's different (T6 ss 19).

#### **4.7.3.3 Social Support**

All the participants spoke of how they valued the support offered by relatives, friends and members of the community but sadly, support for their caregiving role was not experienced by many of them. As Afua said: “ Nothing, I get no support from friends and other neighbours”. Emotional and practical support from a spouse was considered the most important in helping them cope with the caregiving role but only one participant (Eno) volunteered that her husband began providing consistent assistance after he was given accurate information about cerebral palsy at the hospital.

Some participants relied on the help of a sibling and this was often the only way they could temporarily leave the child with cerebral palsy. For example, Akua described the contribution of her older daughter, who although still a minor, provided support care for her brother when they were both living with their grandparents:

I felt bad because the elder one who is seven years did not continue her education and because their grandparents were farmers, they leave him with her sister and go the farm..... Secondly their grandma was old and could not carry the baby (child with cerebral palsy) so she (the sister) was the one carrying the brother (T4 ss 51)

The older daughter also enabled Akua to maintain her involvement with the church. As she explained:

I play an instrument in church so I sit in front and our church too you are not be allowed to carry a baby whiles playing the instrument. So when we go to church I put him at the back with the sister till we close the main service... I let the sister stay with him then I go out to fetch the water (T4 ss 66)

Similarly, Adwoa benefited from the support of another child:

I cannot go anywhere again. If I go out and leave her she cannot do anything on her own, she cannot even drink water on her own. So I have to stay until her sister returns from school then I leave the house that is if I have things to buy in town (T5ss 20).

Some participants were able to rely on others who happen to be around when needed. As

Anna explained: "If people are around our house or the next house, the child can go and stay with them. But if there is nobody, I leave her alone in the house" (T11 ss 14). Another

source of support for some of the participants were extended family members, such as,

parents and in-laws and siblings and this took several forms. For example, Afua's brother

and his wife looked after the non-disabled twin, as she explained: "Because of my child's

condition, my brother and the wife have volunteered to look after her other twin.... My

family think the twin might also be sick if she is allowed to interact with her twin

sister"(T2 ss 20). Akua, sought support from her parents-in-law when she was going

through a financial crisis:

When I gave birth to my first child my family asked me to go to my husband, so he decided to take us to his mother. The rational was that if I go and stay with her it will be better, if his mother cooks,

she will give us some to eat. Things will be better in terms of the care and other things so I agreed to go there but it was a mistake going there I should have stayed here rather (T4 ss 2)

In Akosua's case her grand auntie provided her with much needed emotional support. As she said: "I am always weeping. It is my grand auntie who has been encouraging me to continue to pray and with time he will be well (T10 ss 14).

In contrast, most of the participants expressed their disappointment about the unsupportive attitude of their extended families. Adwoa and Akua perceived this to be a source of sadness and a reminder of the death of their biological mothers. As Adwoa said:

I have lost both mother and father, and the other family members did not receive me warmly so I have advised myself not to go there, right after my father died they shared his properties and because I am the last born I got nothing so I have also gone my way (T5 ss 67)

Similarly, Akua said:

I always wish my mother was alive she would have taken care of him for me so that I can work. I do not want a situation whereby this situation will affect the elderly one's education because I couldn't go to school so I want all my children to go to school (T4 ss 73).

Most of the participants identified the church as a very important source of support. Mena got a break from caregiving when the church members spent time with her child. She said: "It is nowadays that they (church members) come and take her to the church and bring her back and she and her grandmother will be in the house". Nana welcomed church members who visited and offered prayer support. Esi was one participant who received financial support from a Christian non –governmental organization. As she said:

It's the Youth Alive [NGO] members also helped. They help a lot. Sometimes they invite us (mothers of children with disability) to come to the social center. We've been there three times now. Sometimes they give money. Parents of children with disabilities, when we went there, it wasn't everybody they selected. We were four people. Each time they come, they call us to give us something to support us. It was two months ago when they came. We went there on Tuesday and Thursday, since then, they haven't called us again (T6 ss 27).

Unfortunately such support was not available to most of the participants and, in Esi's experience, was not consistent enough to be relied upon.

#### **4.7.4 Summary of section**

The demands that shaped the caregiving role were described by the caregivers as physical, financial and social. Under physical demands, caregivers perceived that lack of skill in handling their children with cerebral palsy caused extreme physical and cognitive exhaustion, which was compounded with lack of assistive devices, lack of support and managing other responsibilities. Extreme financial demand was associated with high cost of intervention, giving up of care because of the caregiving responsibilities and lack of financial support from spouse and family members. The social influence was demonstrated by the society putting pressure on caregivers to conform to their directives. Caregivers also faced social discrimination and stigmatisation which led too social isolation.

## **Chapter 5**

### **Exhaustive description and essential structure of the investigated phenomenon**

#### **5.1 Exhaustive description**

The phenomenon being studied is the essence of caring for children with cerebral palsy living in rural communities in Ghana from the perspective of primary caregivers. The phenomenon could be described under two major themes that emerged from this study:

1. Developing personal beliefs to support the caregiving role
2. The demands that shape the experience of caring

This section presents a summary of the themes and the association between them, and represents the exhaustive description as well as the developed essential structure of the phenomenon. The caregiving process takes the whole being of any individual caring for a child with cerebral palsy. It is all encompassing. Experiences of caring for a child with cerebral palsy are much more complicated than those associated with caring for a child without disability in the same context and are characterised by feelings of desperation not experienced by those who care for a normally developing child. Caregivers are motivated to assume the caregiving role for diverse reasons which include caring in the absence (most commonly the death) of the biological mother, or because the individual was at home but negligent or because the biological parents were overwhelmed with worry about the child's condition or because they had given birth to the child and assumed responsibility.

Caregivers and close family members clearly recognised at an early stage that something was wrong with their child and perceived that the child might be suffering from

a serious health issue and accurately observed when their child failed to achieve the anticipated developmental milestones as compared to other children of the same age. These observations were made right from birth when the child was floppy or later within the first year of life. When the caregivers failed to get an explanation or understanding of the child's condition they were compelled to conceptualise it as having a spiritual cause. Consequently they frequently interpreted the condition through the lenses of their spiritual and religious beliefs. Caregivers also developed a sense of spiritual connectivity between the caregiving process and things happening in the spiritual world instead of within the physical reality. Once caregivers arrived at their own understanding of the child's condition, they began to struggle to come to terms with the diagnosis and actively sought approaches to remediate the child's problems. In addition, the caregivers made conscious and sustained efforts to apply the principles of their religious beliefs to solve their personal problems, minimize, or accept the burden of caring for a child with cerebral palsy.

Caregivers, sometimes before signs and symptoms of cerebral palsy were evident, instinctively knew that their children had problems and without official medical or rehabilitation support, proactively assumed responsibility for developing strategies aimed at improving their child's condition. Caregivers employed strategies based on local remedies and ideas grounded in their own or others' experiences and beliefs. Their motivation of employing a particular remedy or consulting specific individuals was their quest for improvement or recovery of their children, and to gain an understanding of cerebral palsy and the general prerequisites for normal motor development. Caregivers refused, and strongly resisted, any attempts or suggestions of interventions from others that they considered would have negative effect on their child in the early years of caregiving.



However, as the years passed and their child's situation worsened, they came to regret not accepting more of the advice given to them even when the remedy could have caused their child's death.

In caring for a child with cerebral palsy, the caregiver developed and brought into consciousness all their deeply held personal beliefs to support the caregiving role. Their interpretation of their child's situation and their beliefs about cerebral palsy were further developed from the information and the advice they received from people they considered to have knowledge and experience of the condition. Their personal beliefs were intrinsic to them as a person and had their origins in their upbringing and social context. Every action they took in life was influenced by these specific personal beliefs or perceptions and, for most, there was a particular focus on the importance of the central religious belief that God controls every aspect of their lives whether outcomes of situations were judged good or bad.

Caregivers primarily coped with the challenges of caring for their child by disregarding the difficulties, managing on a day-to-day basis and continuing with their lives. Their complete acceptance of their child's condition was based on the belief that cerebral palsy and their subsequent caregiving role came from God. This unswerving belief in God's action and will was more evident in situations where the child with cerebral palsy was a twin. In these situations, caregivers believed that God had given them two things, one bad and one good, and based on their faith in God's mercy they became optimistic that God would heal their children and that these children were destined to become prominent persons in society in the future. In the case of single children, caregivers equated the achievement of developmental milestones with their child's potential for a brighter future

and specifically prayed to God to enable them to observe the significant developmental changes they fervently desired. Caregivers anticipated receiving benefits and blessings from God and this belief supported their love and commitment in caring for their children with cerebral palsy. Enacting and fulfilling the caregiving role to the best of their ability was perceived by caregivers as doing well in the eyes of God.

Caregiver's beliefs also influenced by how they evaluated or judged the standard of care they provided for their child. Central to their perception of being a 'good' caregiver was their ability to provide for the basic needs of the child. The most common needs discussed were provision of food and assisting their children with feeding and bathing. For caregivers the nature of caring was fraught with difficulty and suffering particularly in terms of meeting the ever changing needs of their children with cerebral palsy. In addition to the provision of these fundamental needs, the caregiver also monitored their child's hygiene and dressing particularly for children who had gained a level of functional independence as well as trying to maintain a level of respect for their autonomy. Caregivers depended on the extended family system for support mostly because of the absence of central governmental support.

Caregivers were very aware of the marked activity limitations associated with cerebral palsy and assumed responsibility for assisting their children with these activities. However, these responsibilities imposed considerable physical demands on them. Caregivers identified that training in proper handling techniques could have eased the physical fatigue and injury they experienced as a result of caring for the physical needs of their children. They faced increasingly difficult challenges in handling the child as they grew in height and weight and these challenges were compounded by the neurological and

musculoskeletal complications associated with cerebral palsy. Spasticity was the most significant complication that caused their inability to handle the child. Caregivers appreciated how important it was for them to maintain their own physical strength in order that they would be able to continue to carry and transfer the child on daily basis and as their children grew. This was perceived to be the key to their success as a caregiver. They recognised that the presence of stiffness [spasticity] increased the loss of movement in the child's joints [contractures] and made transporting and carrying the child extremely difficult. However, they had no assistive devices or equipment that could help lift, transfer or move the child. The physical demands of caring for a child with cerebral palsy had a negative impact on the health of the caregivers. Most experienced musculoskeletal pain as a result of continually lifting and carrying the child and they had no one to share these responsibilities or support them in caring for their children.

Caregivers identified some of the activities they found most difficult, such as, handling their children during bathing, and changing diapers and soiled linen. Feeding was also perceived by caregivers to be difficult particularly determining the right food texture, managing the feeding procedure and frequency, and preparing suitable food for their children. These activities took much time and the caregiver had to master the necessary skills mostly by trial and error as no professional advice was available. Furthermore, caregivers identified a diversity of other responsibilities and tasks that required considerable physical energy and effort, such as, going to work, caring for other children, farming, fetching water and hand washing clothes. Because of the many and diverse demands of caregiving the caregiver were rarely able to participate in a social life or assume social roles.

The caregivers acknowledged that all families in rural Ghana were experiencing 'economic hardship' regardless of whether they had a child with disability or not. However, caring for a child with cerebral palsy significantly added to their financial difficulties and they lived in poor and miserable conditions. Most of their limited financial resources were spent on interventions they hoped would improve the child's condition or would result in their complete recovery, such as, spiritual interventions and herbal preparations that, in reality, did not improve the child's condition or quality of life. In addition to paying for such interventions, caregiver frequently had to get extra money to transport the child to the appointments with herbalists and spiritual advisors. Transportation often presented a problem as the children were physically fragile and frequently became aggressive on public transport meaning they had to hire a car or taxi.

The consequences for the caregiver of not being able to work and make an income were diverse and had a negative effect on their lives and their child's and, as well, they were the source of considerable personal stress and anxiety. Lack of money to provide basic needs, such as, food for themselves, their child and other family members, inability to pay their main bills, for example, electricity and rent, were the predominant concerns. Caregiver depended on occasional charity from friends and other family member and experienced considerable emotional stress when they were unable to provide the child with other important needs such as health care, which for most was difficult or impossible. Most caregivers experienced lack of support from spouses and family members and this often lead to them to wish they could or to consider giving their children up to orphanages or social welfare. In most situations the fathers were absent and had abandoned both child and

mother in terms of emotional, practical and financial support when they learned their child had a disability.

The caregiving process was influenced by the demands made by individuals in the community and the need for the caregiver to conform to their society's expectations. Caregivers frequently complied with recommendations made by members of the community and acted on these without evidence of veracity or effectiveness. Issues related to their acceptance of this type of advice shaped their accounts of taking care of a child with cerebral palsy as they frequently identified how society's expectations and attitudes conflicted with own personal beliefs and values especially in terms of their efforts to find interventions to help their children. This conflict caused considerable emotional distress particularly as often they agreed with, and acted on, suggestions from others particularly family members but privately disagreed with them. Caregiver made these decisions in order to conform and align themselves with their society's roles, norms and expectations and to maintain their identity within the community despite the fact that the suggestions and opinions offered them were often not positive. Caregivers and the children with disability were discriminated and stigmatised. Discriminatory attitude from the society influenced the caregiver to change their place of work and residence. Caregivers experienced humiliation and personal failure for delivering a child with cerebral palsy and felt guilty for disgracing the family.

The negative consequences of the caregivers perceived inability to balance their strengths (religious and spiritual beliefs) and stressors (environmental factors and actual demands) resulted in feelings of immense sorrow and despair that increased over the years as they came to accept the reality of their child's condition. Caregivers could identify a

number of factors that triggered these feelings of despair and sorrow, such as, the recognition that their children were not able to achieve the anticipated developmental milestones, their inability to obtain accurate information about the child's condition, their perception that their child experienced intractable pain and suffering, as well as feeling stigmatized by their community and frustrated by the relentless demands of caregiving. Caregivers frequently characterised caring as: 'suffering', 'hardship', 'tiring', 'unbearable', 'difficult' and 'sacrificing'. Their descriptions of the effort involved in caring for the child were closely linked to the health of their children. The isolating nature of caregivers responsibility for their children which must for them stretch unrelentingly into the future with no relief in sight. However caregivers were committed to an ongoing love for their children and somehow accepted this responsibility and managed to remain focused on what was the best for the child with all their efforts. Even though caregivers felt like they frequently failed, they remained focused on being of benefit and keeping their child safe.

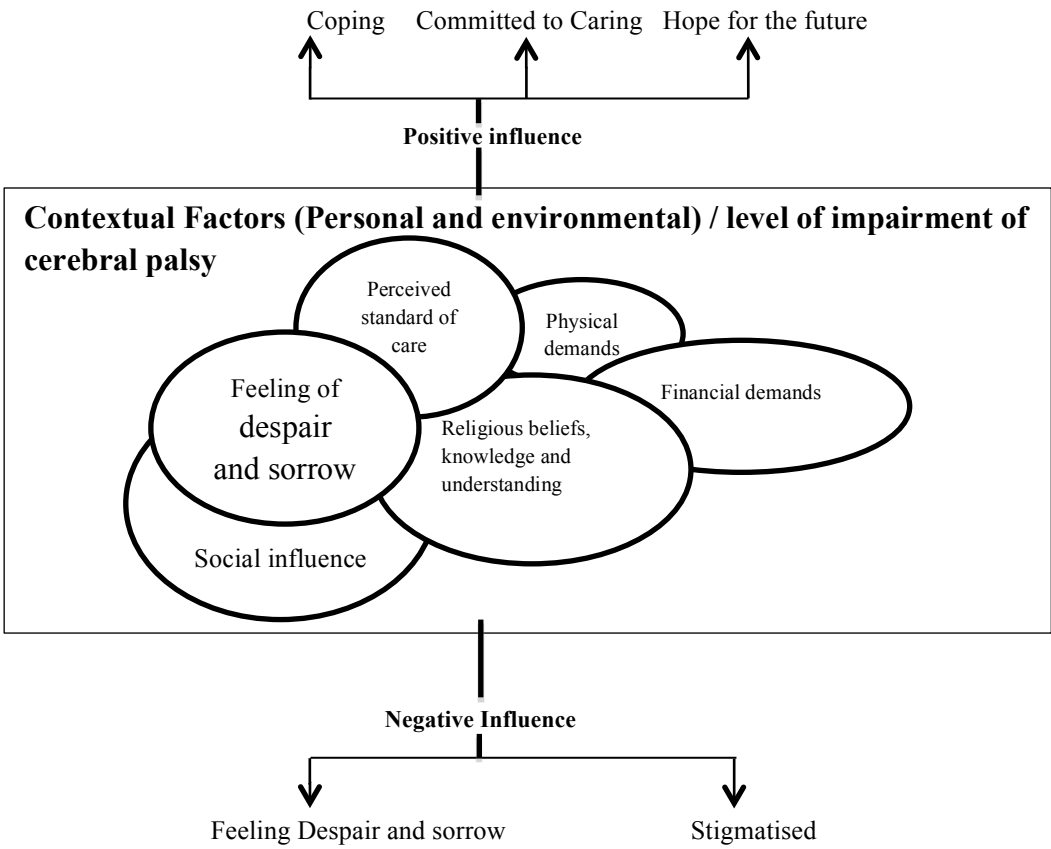
## **5.2 Essential structure of the phenomenon**

The essential structure addresses the essence of the exhaustive description of the phenomenon. Caregivers of children with cerebral palsy experienced the caregiving process in their unique environment and were influenced by their personal factors like their age, level of education, culture, attitude, sense of empowerment and financial resources. Significantly apart from the intrinsic factors the caregivers developed religious and spiritual beliefs to support the caregiving process (main theme 1). The impairment of cerebral palsy was also associated with the demands of caregiving (main theme 2). There

was also a strong interconnectivity between all the secondary themes as shown in figure 5.1.

The first secondary theme ‘interpretation of the child’s condition through religious beliefs’ under the emergent theme ‘developing personal beliefs to support the caregiving role’ had an association with the other secondary themes “ physical demands, financial demands, social influence, perceived standard of care and feeling despair and sorrow’. The act of fulfilling the religious and spiritual requirements and responsibilities was an essential component contributed to the theme cluster ‘managing other responsibility’ which is included in the theme ‘physical demand’. Likewise there were financial implications in performing religious responsibilities, hence forms a link to the secondary theme financial demands. The cultural lens of interpretation the child’s condition is acquired from the theme social influence. Interpretation of the child’s condition from religious and spiritual belief could cause feeling of despair and sorrow if the caregivers could not comprehend the perceived interpretation. The theme clusters, acknowledging the child’s developmental delay and feeling stigmatised contributing to the secondary theme ‘feeling of despair and sorrow’ have their roots from the secondary themes ‘ social influence and perceived standard of care’. Caregivers in performing their role try to achieve a balance within the interconnectivity of all the themes amidst their contextual background and the sequel of cerebral palsy. The caregivers achieved a positive balance when they demonstrated coping, committed to caring and hope for the future. On the other hand if they achieved negative balance then they demonstrated feeling of despair, sorrow and stigmatised.

**Figure 5.1 Essential structure of caring for a child with cerebral palsy in rural Ghana.**



In the next chapter a discussion is presented to demonstrate the position of the interconnectivity in available literature and conceptual frameworks.



## **Chapter 6**

### **Discussion**

#### **6.1 Introduction to the Chapter**

This study explored the meaning and understanding that caregivers of children with cerebral palsy attributed to their experiences of the caregiving process. The previous chapter presented the findings derived from and illustrated by the narratives of the caregivers who experienced the phenomenon - “to the things themselves” - as stipulated by van Manen (1990, p.184). My desire in choosing to use a descriptive phenomenological approach was to develop an in-depth understanding of “how individuals who care for children with cerebral palsy in a rural Ghanaian context, but who have not received any form of rehabilitation, experience the caregiving role”. In accordance with this approach and Colaizzi’s data analysis framework, discussed in the Methodology chapter, an exhaustive description of the phenomenon and the essential (or fundamental) structure of the experience of caregiving was written to summarise the main findings and the essences they represented and how these are interconnected is presented in chapter 5. The aim of the following discussion of the two main themes, ‘Developing personal beliefs to support the caregiving role’ and ‘the demands that shape the experience of caring’, is to critically compare and contrast the findings with the relevant theoretical and research literature in order to highlight the new insights and in-depth understanding of the experience of caregiving in rural Ghana offered by this study.

## **6.2 Summary of the Essential Structure of Caregiving**

In accordance with descriptive phenomenological approach, the relevance of this section is to critically summarise the essential structure of caregivers' experiences of caring for children with cerebral palsy, and highlight the significance of relevant theories in promoting linkages between concepts.

The World Health Organisation (WHO), International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) emerged as a significant conceptual framework with the potential to provide the foundation for rehabilitation professionals', including physiotherapy, practice with a universal language to discuss issues pertaining to functioning, disability and related phenomenon (Jette, 2006). The ICF model directs service delivery towards a bio-psychosocial approach in which the complex interaction between impairment and contextual factors is considered in clinical decision-making (Rosenbaum and Stewart, 2004). This complex interaction between the impairment of cerebral palsy and the contextual factors – environmental and personal - were highlighted in this study. The impairment of cerebral palsy causes significant developmental delay and low level of functional capabilities as compared with other children and total dependence of the children on the caregivers. Caregivers in this study, in fulfilling their care responsibilities, observed their children closely and identified their children's developmental delay and constantly sought interventions that might benefit their children as well as maximised their efforts to protect their children from harm. The ICF model recognises the central importance of personal factors, such as, age, ethnicity, educational level, social and financial status, general health, lifestyle, occupation and sense

of empowerment, but these factors are classified in the ICF “because of the large social and cultural variance associated with them” (WHO, 2001; Roush and Sharby, 2011).

The significance of personal factors, as discussed in the ICF, was clearly evident in the findings of this study. The respective ages of the caregiver and the child with cerebral palsy were associated with different interpretations of the caregiving process. The association between the burden of care and the growth of the child in respect to weight and height were revealed in the participants’ narratives. The child’s personal care, and the need to lift and carry them, gradually became more difficult as the child aged and the caregivers went through physiological changes associated with their own aging processes (Burkhard, 2013). Furthermore aging of caregivers brings not only physical concerns but significant psychological stress which includes fear and anxiety as they anticipate what will happen to their children when they die or they are sick.

The participants’ discussed a range of physical and financial demands associated with their caregiving role and which shaped their caregiving experiences. They expressed the emotions, psychological stresses and frustrations linked with the demands of caregiving that prevented them fulfilling their personal desires, such as, involvement in social activities. However, most of the participants found the time to go to church in order to fulfil their spiritual interest. In contrast, participants in Burkhard’s (2011) study actively sought out support and arranged time away from their caregiving responsibilities and worked outside home. These participants were also committed both morally and emotionally to promoting the well being of their children and providing for their needs.

Level of education was also significant in this study as 8 out of 12 of the caregivers had never been to school. In a survey study conducted in Pakistan by Aslam and Kindon (2012) investigated the relationship between parental educational level, child health and health seeking behaviour. The result revealed a higher positive association between mother's level of education and child's health especially the weight and height. Better health behaviours such as healthier diet, better hygiene and knowledge about the importance of immunisation were seen more among educated mothers than the uneducated. In addition, similar to this study, participants in Aslam and Kindon's (2012) study demonstrated their ignorance of basic health issues, had unhealthier diets, and engaged in indigenous unhealthy practices due to the lower level of education.

The WHO (2001) also identified ethnicity as an important personal factor. The caregivers' narratives demonstrated their willingness, and their need, to be an accepted member of their community and culture by conforming to cultured tailored practices. The culture had both positive and negative effects on the caregiving process. Positively the traditional extended family system offered support to the caregivers. Negatively the caregivers' family and societal context exerted pressure on them, particularly on relation to healer seeking activities. Another personal factor identified by the WHO (2001) - sense of empowerment of persons with disability and those who support them – was also evident in the study findings. The caregivers were less empowered in terms of being inadequately informed about the condition of their children, the skills they needed to effectively and safely physically handle and manage their children, and they lacked the social empowerment to participate fully in social activities with their children with cerebral palsy.

The participants also discussed financial resources, mostly their lack of adequate resources, as a personal factor that could facilitate or act as a barrier to the promotion of their child's well-being.

The ICF defines environmental factors as the social, attitudinal and physical environments in which people live (Lawlor et al., 2006; WHO, 2001). The participants in this study discussed a diversity of environmental factors, for example, the physical environment, social attitudes, the experience of being stigmatized, the larger government economy, and availability (or lack) of supportive families. The dimension of environment factors dimension in the ICF model is strongly associated with the social model of disability (Lawlor et al., 2006). As Sykes (2008) suggests "The interaction between an individual and that individual's contextual factors is an important facet of the ICF's bio-psychosocial model of functioning and disability" and, in Western countries, the human rights movement and the influence of the social model of disability has resulted in a shift towards a rights-based treatment of disability (p. 112)

According to the ICF model (WHO, 2001), disability is interpreted as a socially created construct. The social model of disability significantly influenced this study because the model provided a better understanding of the interplay between the social context and caregivers' experience. In the social model people with disability and their families are conceptualised as a minority in the society that have been denied the basic rights of accorded citizens of that society (Smart, 2009). In this study the caregivers' experiences were impacted by multiple factors, such as, oppressive social attitudes like stigmatisation, discrimination, fear of insults, being pitied and feeling isolated coupled

with a lack of rehabilitation services and social support. These findings were similar to those of a phenomenological study conducted in Uganda (Hartley et al., 2005) which explored how families with children with disability living in rural areas coped with the needs of their disabled children in their community and the problems they faced as well as the strategies they used to overcome the problems. Participants in the study also discussed the negative attitudes of others that they faced including rejection and abuse leading to feelings of loneliness and isolation. Such research findings highlight the perception “that disability is an individual problem requiring private solutions rather than, [as promoted by the social model of disability], a matter of socially produced barriers requiring public and political solutions” (Roush and Sharby, 2011, p.1718). The participants sought ‘private solutions’ for their child’s health needs by engaging in traditional practices that could harm their children and negatively affect their health. Furthermore a recent qualitative study conducted by Naami (2014) in the northern part of Ghana revealed the socially produced barriers that restricted the full social and economic participation of women with disability. In using both in-depth interviews of 10 physically challenged women between the ages of 20 and 45 years and 2 sets of focus group discussion of 14 stakeholders from government and civil society organisation, identified the barriers to be “attitudinal, architectural, transportation and information” (p.21). The barriers identified in this study agree with barriers that caregivers of physically challenged children experienced in performing their roles. According to Naami (2014) the social model of disability offers a comprehensive framework for ensuring the respect of the rights of persons with disability.

According to the Convention on the Rights of the Child (United Nations, 1990) children have the right to be given health care according to their unique health needs. The United Nations Children Emergency Funds (UNICEF, 2006) refers to child protection as measures aimed towards preventing and responding to violence, exploitation and abuse against children including harmful traditional practices. In this study, participants revealed that their children with cerebral palsy were abused and suffered harm during the process of seeking for intervention. Examples of incidences were reported, such as, a mother forced to give perceived ‘dwarf concoction’ to her child, and a father who physically abused his child because the child refused to drink medication and other substances, that violated the rights of the children with cerebral palsy. According to a UNICEF report (2011) an effective child protection system requires a strong policy framework. Fortunately the government in Ghana, in corroboration with UNICEF, has developed a new child protection policy that is culturally appropriate and seeks to protect children from abuse, exploitation and maltreatment of children (UNICEF, 2013).

The participants actively worked towards striking a balance between their own interests and the interests of their children by developing a range of personal beliefs to support their caregiving role and multiple strategies to satisfy the demands of caring. Striking this balance was on going as the demands of caregiving continually shaped the experience of care. The participants discussed different sources of strength they turned to in their efforts to achieve this balance, such as, focusing on the present, their spirituality and faith in God, and their determination to combat the burden of caring, and the stresses associated with financial demands and role conflicts. The Integrative Harmony Model

(IHM) (Haley and Harrigan, 2004) may offer a way of conceptualizing these efforts as it proposes that individuals have a unique perception of stressors and strengths that is influenced by their unique culture or world view. According to Haley and Harrigan (2004) the principle informing this model is that there is a connection of dynamic energy flow between the perceived strengths and stressors of every individual and it is influenced by the present experience and sense of harmony. Haley (2009) considers this harmonic state to be individualistic and it is the core equilibrium that is reached when there is a free flow of energy between perceived strengths and stressors. Interestingly, the participants' explanations of the efforts they made to achieve balance in their lives were similar and this may be because the participants shared the same cultural context and environment. Ratliffe and Haley (2002) view harmony as each person's view of the world and this view influences whether they will attain a position of empowerment (energy/ connectedness) or victimization (judgment / dualism). In this study, the participants assumed both positions i.e. some were positively committed to caring, coping, hope for the future, and acceptance of their child's condition and others experienced more negative unresolved feelings of isolation, frustration, and felt stigmatized.

It was clear that the demands of caregiving put caregivers at a higher risk of health and safety complications. Hence caregivers need the support of rehabilitation professionals to teach them about cerebral palsy, short and long term consequences of living with a child with the condition as well as providing them with the skills and information needed to provide effective and safe care. The philosophy of rehabilitation is about enabling, facilitating and empowering individuals and those that support them. Empowering the



caregivers with the knowledge and skills required to care for their children with cerebral palsy would promote their well being and that of their children. The participants – all caregivers – in this study had no experience of rehabilitation and this contributed to the unique context of this study.

### **6. 3 Discussion of Theme 1: Developing personal beliefs to support the caregiving role**

The participants in this study demonstrated a development of personal beliefs based on their unique context to support their caregiver role. The poor environmental conditions, lack of support, poor living situations, negative social attitude and lack of understanding of their child's condition, all contributed to the development of unique personal beliefs to support their role as caregivers. These unique personal beliefs were clearly based on their previous knowledge, and the information and advice they received from people they considered to be knowledgeable and experienced about cerebral palsy, and their moral sense of duty and responsibility to the child. The participants expressed very strong specific spiritual and religious beliefs upon which their lives were built and which influenced every action taken. These personal beliefs were geared towards their interpretation of cerebral palsy and grouped into three secondary themes, religious and spiritual beliefs, perceived standard of care and feelings of despair and sorrow, which will be discussed separately in relation to the literature.

### **6.3.1 Interpretation of cerebral palsy through religious and spiritual beliefs**

The first secondary theme focused on the influence of participants' spiritual and religious beliefs on the caregiving process. All the children with cerebral palsy in this study had overt physical challenges and co-morbidities that the participants had, over time, observed and determined that there was "something was wrong" with their children. Inability to get an explanation of the condition caused most of the participants to conceptualise it as a condition of spiritual origin. Obladen (2011), in his scholarly article on "lame from birth, early concepts of cerebral palsy," described how cerebral palsy was conceptualised. According to Obladen, when the cause of cerebral palsy was not known during the 17<sup>th</sup> century, it was attributed to spiritual causes such as witchcraft, God's wrath and the evil eye. Interestingly the phenomenon of attributing the cause of cerebral palsy to someone or a deity still persists in the 21<sup>st</sup> century. Children with cerebral palsy were popularly referred to as 'spirit child' in this study. The mixed method approach consisting of ethnographic field work and demographic analysis study of Denham et al.,(2010) conducted in the Northern Ghana provided a better understanding of the spirit child phenomenon. The study employed diverse data collection approaches including participant observation, unrecorded interviews, informal interactions, over 100 semi structured interviews and open ended questions. The participants of Denham study were "community members, community health nurses and family members and 15 concoction men (ritual specialist involved in treating spirit children with symbolic items and sometimes with poisonous and non-poisonous herbal concoctions)" (p. 609). According to the study,

participants perceived that ‘spirit children’ are “bush spirits born into a family in human forms so that they can get access to the good things in the house” (p.611) and destroy them. The perception about children with disability was similar to caregivers in this study report on the misconceptions about disability in their community. The decision taken by the family is often complex (Denham et al., 2010). It was revealed in this study, a number of proposals that the families of children with cerebral palsy offered to get rid of the children. The decision included, going to leave the child at the river bank or the forest so that he or she can go back to where they came from. Again some of the children were given some concoctions to test if they were spirits or humans. When that child dies after drinking the concoction, the family assumes that child was a spirit hence could not tolerate human fluid. The misconception of cerebral palsy in most parts of the country and especially the rural settings is gradually becoming alarming. The participants of a number of studies conducted in Africa, shared a similar traditional and an uninformed view of cerebral palsy (Hartley et al., 2005; Gona et al., 2010; McNally and Mannan, 2013, Olawale, Deih and Yaadah, 2013).

The study conducted by Denham et al. (2010), indicated that the community members perceive the prevalence of spirit children are decreasing, hence the authors attributed the assertion to improved maternal health care programmes (p.614). Nevertheless there are different opinions about the trend and incidence of cerebral palsy. Enweronu-Laryea et al. (2008), have the notion that improved neonatal care may significantly increase the survival rate of premature infants who would have previously died and at higher risk of developing cerebral palsy. Evidence from studies worldwide

reveals that the prevalence of cerebral palsy is associated with race and ethnicity and influenced by social class (Wu et al., 2011; Yeargin-Allsopp et al., 2008; Hammal et al., 2004; Oddings et al., 2006). The trend of the prevalence of cerebral palsy in literature suggests the condition cannot be eradicated, but prevention and early detection programmes should be improved. Information about cerebral palsy should be easily accessible especially in developing countries.

Gona et al (2010) conducted a phenomenological study exploring the challenges and coping mechanisms of caregivers of children with disabilities. Gona and colleagues' described caregiver challenges under the themes; expectation that hospital staff would give them information about their child's condition, fear of the future, rumour- mongering and poverty. On the contrary the participants in this study did not know where they could get the information they needed. As in my study, the participants in Gona et al's (2010) study developed a strong link between the child's disability being the result of influence by evil spirits, witchcraft or as a punishment from God and applied spiritual interventions. The sample size in their study was larger - 20 caregivers, 10 community members and 5 teachers compared to my study although no explanation for inclusion of the latter two groups were given. Similar to this study, participants' experienced financial challenges and looked for external support.

The participants in this study drew considerable psychological strength from their faith in God. Their religious and spiritual beliefs were credited with helping them to cope, accept their child's condition, and to commit to caring largely because of the benefits and blessings of God they believed they would receive and the hope for the future this gave

them. These findings support those of previous authors (Treloar, 2002; Speraw, 2006; Geere et al, 2013; Gona et al, 2010; Green, 2007) namely that families find comfort in their personal spiritual beliefs and their faith that God will reward them. Three of the studies were conducted in the United States of America (USA) (Treloar, 2002; Speraw, 2006; Green, 2007) and two in Kenya, Africa (Geere et al, 2013; Gona et al, 2010). The similarities found in these studies indicated that caregivers of children with disability from both Western developed countries and developing countries relied on their spiritual belief to cope with the burden of caring. For example in a mixed method study, Green (2007) interviewed 81 mothers of children with disability in Florida, USA and identified that the participants perceived caring as performing God's work for which they would receive blessing and they expressed that they felt 'good in their heart' despite the physical discomforts and pain, and perceived stigma they associated with the caregiving role. These issues of stigmatization are discussed in more detail in section 6.3.3: Feelings of despair and sorrow.

Many of the participants in this study considered that God controlled every aspect of their lives whether the outcome was good or bad and their involvement in church was a source of both social and spiritual support. An earlier qualitative research study conducted by Treloar (2002) also in the USA investigated the influence of spiritual beliefs of 13 parents of children with mixed developmental disabilities and 9 adults with physical disability and resulted in similar findings. The participants in Treloar's study reported that their churches demonstrated a level of discrimination towards persons with disability but they felt that the benefit of social support they received through their participation in

church activities outweighed the discrimination they experienced. Belonging to a religious denomination was found to be beneficial in the caregiving process. Dollahite (2003) conducted a study in Utah, USA with the aim of exploring the experiences of fathers who belong to the Latter-day Saints Church. Thirty-five fathers who provided care for their children with special needs were interviewed. The author concluded that: “fathers’ beliefs and expectations inspired them to make and keep a commitment to a sacred responsibility of loving, serving, and caring for their children with special needs” (p. 237). This conclusion resonates with some of the participants’ who belong to other Christian denominations and believe that God gave them their children to care for and this faith in God’s purpose promoted their commitment to caring for them.

Concerning clinical practices, King et al. (1999, p.1297)) conducted an interesting although older survey study to investigate the effect of spiritual beliefs on the clinical outcomes of illness with 250 patients admitted to a London teaching hospital in the United Kingdom. The authors concluded that individuals with “stronger spiritual beliefs did not do as well clinically as those who adhere less strongly” (p.1297). The strong spiritual beliefs appeared to prevent the participants from adhering to recommended medical treatment protocols. Unfortunately no other more recent studies were found, after searching six different databases (Academic Search Complete, CINAHL complete, Medline, Religion and Philosophy collection, Health Source – Nursing Academic Edition, Google Scholar), that addressed the impact of religious and spiritual beliefs on adherence and clinical outcomes. While not specifically investigated in this study, a number of the participants did express a preference for prayer over actively seeking medical assistance, for example,

one participant prayed for an injured child instead of sending the child to the hospital. Such attitudes are deeply rooted in spiritual and religious beliefs and have no little or no reference to scientific or physiological evidence.

### **6.3.2 Perceived standard of care**

The second secondary theme focuses on the participants' perceptions, expectations and evaluation of the caregiving process. The participants identified the caregiving role as 'a hard task' that required the caregiver to demonstrate certain essential characteristics, such as, patience, love, prayer and determination and to devote time specifically for the child with cerebral palsy. Caregivers' narratives suggested the development of a strong bond with their children who were fully dependent on them. Kittay (1999), wrote a seminal article based on , her experience as a philosopher and a mother of a child with disability, and acknowledged the similarities in the goal of mothers' of children with disability and typically developing children, for their children to attain independence. However, she suggested that the attitude of individuals caring for physically dependent persons with disability is altered from the usual maternal caring practices; "when the commitment to the child (with disabilities) has been made, preservative love comes to occupy an overriding central place in one's maternal practice" (Kittay, 1999, p. 16). She stressed that children with severe disability may depend on their caregivers all their lives and advocated strongly that "dependency is often socially constructed" (p.17), when there are no formal alternative care system in place or other caregiving support from other family members. Mothers of adolescents with cerebral palsy participating in Burkhard's (2011) study described the love they felt for their adolescent children with cerebral palsy

as unconditional, that is, they loved them regardless of their behaviour or actions. Caregivers in this study held diverse opinions about what is caring and why they were caring for their children with cerebral palsy. They had mixed feelings about caring. These ranged from provision of the needs of the care recipient to perceptions that caring was difficult, involved suffering and giving their best. Caregivers in this study and Geere's et al's (2013), conducted in Kenya, gave more complex responses to the caring role and responsibilities and expressed the need for support for the caregiving role in contrast to Burkhard's (2011) findings from USA where there exists a more effective and reasonably efficient health care system and supportive formal social system. Hence the difference in caregivers' perceptions about the caregiving role could be linked to the context and supports Kittay's (1999) opinion that dependency is socially constructed.

In this study, most of the participants had no opportunity to access an official medical diagnosis, rehabilitation support or any information about cerebral palsy. As a result, in addition to fulfilling their caregiving role to the best of their ability, they proactively assumed responsibility for developing strategies, based on local remedies and ideas, aimed at improving their child's condition. The participants' emphatically stated that the healthcare professionals they did consult were unable to provide them with relevant or accurate information about the condition of their children. This is clearly linked to the shortage of qualified expert health professionals knowledgeable in management of cerebral palsy in primary or community health care in Ghana and other Africa countries as indicated in Donald et al's (2015) report. This report was generated from the themes that emerged from a meeting in South Africa of doctors from twenty-two



African countries including Ghana with the goal of providing more consistent services, that is: “to share information on their services, capacity, approach to diagnosing and managing children with cerebral palsy as well as to propose service needs and future research” (p. 965). Hence the public being ignorant of the status of the health care providers at the primary health care level accepts and assumes what they offer as what they can receive from orthodox sector. Due to the limited access to health services, individual in the rural communities have little knowledge about the health system and what they should expect from doctors.

### **6.3.3 Feelings of despair and sorrow**

The third secondary theme of ‘feeling of despair and sorrow’ represented the emotional outcomes of the caregiving process experienced by the participants. Caregivers felt increasing and immense sorrow over the years as their children aged. They were unable to recognise any recovery or improvement in the functional capabilities of their children. In this study a number of triggering factors for feelings of sorrow and despair were identified: acknowledgement of the child’s developmental delay, the perception that child is experiencing pain and suffering, the lack of understanding of the child’s condition, and feeling stigmatized. The experiences of sorrow and despair appeared to change over time. The description of ‘sometimes, always and often’ used by the participants depicts the frequency and duration characteristic of their experiences of sorrow and despair.

In an early article Copley and Bodensteiner (1987) first conceptualized the dynamic nature of the “grief over the loss of an idealized normal child following the birth of a disabled child as a characteristic of chronic sorrow” (p. 67) experienced by parents. More

recently, other authors (Masterson, 2010; Roos, 2002) have explored the chronic sorrow experienced by parents of children with disability over a period of time beginning from them being informed about the diagnosis. These studies found that chronic sorrow is intensified especially during critical development milestone periods when parents' perceptions about their child's achievement of specific developmental milestone were associated with loss and grief. Participants in this study experienced sadness particularly when they observed the physical and cognitive differences between their children and others.

Roos (2002) suggests that the experience of chronic sorrow and grief are different. According to this theory feelings of grief can be resolved over time when the object of grief is no longer present. In contrast, when caring for a child with disability, chronic sorrow is continuously felt as long as the child lives. Masterton (2010) conducted an exploratory study involving mothers of older children with cerebral palsy in Kansas. USA. The themes discussed by Masterton (2010) were very similar to those reported in this thesis particularly in relation to the sources of chronic sorrow experienced by caregivers of children with cerebral palsy, such as, fear of the future, loss of hope, frustration, exhaustion, sadness and financial challenges. In this study, participants associated their feelings of sadness with thinking about their children's disability and its effects on their lives and as a result they tried to ignore them and not think about the future. Grandmothers in this study chose to care for their grandchildren with disability in order to spare their own children (the child's parents) the chronic sorrow and grief associated with caregiving.

Stigmatisation was found to be very significant in this study. Both enacted and felt stigma were experienced by participants. Participants who were interviewed referred to incidences in which they were discriminated against by other people because of their children's disability. This a form of enacted stigma, described by Scambler (2004:33) as events of discrimination against disabled people. Feelings of stigmatisation in this study were also a trigger for sorrow and despair, but a rigorous search found no other studies that addressed this factor. However, Hazmat and Mordi (2007) who conducted a study in Nigeria with the aim of exploring the impact of caring on the health of caregivers of children with cerebral palsy, and found that feeling stigmatised contributed strongly to participants' experiences of emotional stress. The participants in Hamzat and Mordi's study were biological mothers caring for their disabled children who experienced a sense of humiliation, and felt ashamed and personal failure for having giving birth to a child with cerebral palsy. These findings are similar to those reported by Green (2007) who investigated the benefits and burdens of mothering a child with a disability. The author concluded that the participants' perception of stigma had a strong impact on the social burden and emotional distress they experienced and the lives of mothers of children with cerebral palsy may be much more complex than generally assumed.

"Felt stigma" refer to the shame associated with having this attribute and/or "the fear of encountering enacted stigma" ( Scambler, 2004, p. 33). The feeling of shame and stigmatization experienced by participants may be related to their previous experiences of and perception about persons with disability. As one participant in this study stated, "children like this do not need to be brought to where people gather", indicating that

inevitably caregivers are influenced by the values and attitudes of the society in which they are raised. Prior negative attitudes towards people with disability are most likely changed when a relationship is established with a child or adult with disability. Enculturation and the associated embedded negative beliefs and attitudes about 'others' in society may be difficult to alter, however, the participants in this study did appear to have become advocates for their children. As Goodman (1978), a constructivist philosopher, said: "world making as we know it always starts from worlds already on hand; the making is remaking" (p.6). The participants' narratives portray the internalised conceptualisations of disability they hold and how these are embedded in what their society endorses or supports.

Participants reported stigmatized and discriminatory attitudes held by the community members that resulted in them losing their jobs and having to change their area of residence or place of work. Caregivers were also blamed for their child's condition and they were denied of family support. Huang, Kellett and St John's (2010), study clearly revealed that the "mother of a child with disability being blamed for the child's condition could result in dysfunctional family relations and poor support" (p. 1219). The authors identified two underlying aspects of the cultural context that influenced these perceptions: (1) the traditional belief that a child's parents, family members or ancestors may have done some misdeeds to merit the child's condition, and (2) social stigma, discrimination and rejection of persons with disability within the society. These perceptions also highlighted in this study. Furthermore, Huang, Kellett and St John's (2010) findings supported the impact of discrimination reported in this study. They reported high levels of psychological

stress experienced by caregivers of children with cerebral palsy that are related to lack of family acceptance and support, and the degree of stigmatization they experienced. The feelings of guilt, stigma, isolation, self-pity and shame experienced by the participants in my study are reflected in previous studies (McNally and Mannan, 2013; Moore, 2005; Bourke-Taylor, Howie, and Law, 2010; Huang, Kellett and St John's (2010). For example, in Huang, Kellett and St John's (2010) phenomenological study on the experiences of mothers of children with cerebral palsy after learning their child's diagnosis, revealed that the mothers experienced "shame, a sense of inferiority, self-debasement and social rejection" (p. 1214) related to delivering, and caring for, a child with cerebral palsy in the Taiwanese culture.

McNally and Mannan (2013) conducted a phenomenological study in Tanzania with the purpose of gaining insight into how having a child with disability impacts participants' lives. The authors provided a comprehensive description of the participants' experiences in an African context and social environment. Their study findings were similar to those reported in this study, that is, participants experienced very little social support. Participants experienced overt stigma and discrimination in the form of gestures, such as, pointing, laughing, and staring and rejection by family members, and half of the participants' reported that their husbands left them once they knew their child was disabled, thus supporting this study's findings. In contrast, in Milbrath et al's (2008) study conducted in Brazil, five of the six participants described their husbands and family members as their main support network that helped them to adapt to their caregiving role. The differences in findings could be due to the differences in context. According to

Milbrath and colleagues, “ the people comprising the social support network and the functions they perform in the family change according to the social, culture, financial and historical context” (p.430). Milbrath et al’s (2008) results suggest that positive social support, such as financial, emotional and practical help in caring for the child with disability is essential in reducing the stresses associated with caregiving. Social support from neighbours and from a spiritual community was shown in a number of studies (Hartley et al., 2005; Scheidegger et al., 2010; Gona et al., 2010) to promote coping and contribute to the well-being of the caregivers.

#### **6.4 Discussion of Theme 2: The demands that shape the experience of caring**

The second main theme focused on the diversity of demands that shaped the participants’ experiences of caring for a child with cerebral palsy and caregivers’ perceptions of the effort required to be successful in the role. The meanings attributed to these experiences were grouped in three secondary themes: physical demands, financial demands and societal influence and these will be discussed in relation to the relevant research literature.

##### **6.4.1. Physical demands**

The participants described the characteristics of the physical burden of caring using expressions like ‘suffering’, ‘hardship’, ‘tiring’, ‘unbearable’, ‘difficult’, and ‘sacrificing’. As caregivers they had to assume the responsibility for assisting their children with cerebral palsy with all activities of daily living that required different competencies than those usually associated with caring for normally developing children. One of the unique

competencies that needed to be acquired was proper handling techniques. The participants identified and shared the opinion that proper handling techniques could have eased the physical fatigue they experienced as a result of caring for their children. They all faced increasingly difficult challenges in handling their children as they grew in height and weight and these challenges were compounded by the neurological and musculoskeletal complications associated with cerebral palsy. Caregivers identified some of the activities they found most difficult as handling their children during feeding, bathing, changing diapers and soiled linen. These findings were similar to those of previous studies that focused on the physical impact of caring for children with cerebral palsy (Eker and Tuzun, 2004; Geere et al., 2013; Burkhard, 2013; Dalvand, 2015).

Eker and Tuzun (2004) conducted a survey study in Turkey to evaluate the quality of life of mothers of children with cerebral palsy and mothers of children suffering from minor illness. Their findings suggested that constantly having to lift, position and transport their children with cerebral palsy was a contributing factor to the mothers' perceived decreased quality of life. The authors identified the most common tasks requiring the skill of manual handling as heavy lifting and turning, bathing, helping the child use the toilet, getting the child to bed, dressing, and assisting the child to move. Similar to this study, none of the participants in Eker and Tuzun's (2004) study had any training in manual handling techniques or access to assistive equipment to support the caregiving role or the child's mobility. Other studies, conducted in rural communities in developing countries (Geere et al., 2013; Hartley, 2005; Borg et al., 2009), also identified the need to provide

caregivers with training in manual handling skills and the use of assistive devices and to facilitate access to appropriate devices.

Caregivers in this study identified other responsibilities they were required to perform in addition to caring for the child with disability. These included going to work, caring for other children, farming, fetching water and hand washing of clothes. Dalvand et al (2015) also identified a similar list of activities in their study in Iran of the co-occupation of mothers of children with cerebral palsy and the associated challenges to their caregiver roles. Dalvand et al's findings included activities, such as, organising treatment follow-ups, trying to rehearse rehabilitation exercises, accompanying the child to school, and assisting with homework that were not evident in this study. In the rural Ghanaian context in which this study was conducted these issues were not relevant because there were no available rehabilitation services and none of the children being cared for attended school.

Sullivan-Bolyai and colleagues (2003) proposed four domains of caregiving responsibilities: Managing illness, identifying and accessing community resources, maintaining the family unit, and maintaining self. The findings of this study were congruent with these domains. The responsibility of managing illness or disability related to theme clusters, such as, seeking for spiritual interventions and strategies to improve the child's condition. The domain of identifying and accessing community resources related to the participants' seeking support from friends and engaging in community church activities. The participants in this study did not explicitly address the fourth domain of maintaining self. One caregiver did say: "I don't concentrate on myself, I plan everything



around the care of my child” but strategies by which the participants might have sustained their own wellbeing were not evident in the data. In contrast, Kuo and Lach (2012) identified a theme of caring through sacrifice. The authors reported that the study participants – individuals in Taiwan who care for a sibling with cerebral palsy - explicitly described sacrificing many of their own ambitions and plans in order to support their commitment to caring for their sibling. This included choosing a husband who would be willing to compromise the Taiwanese cultural beliefs about persons with disability and support their caregiving role.

The participants in this study reported not having anyone to share the caregiving responsibilities with, despite the increasing physical demands of caring for their child with cerebral palsy. Appelbaum and Smolowitz (2012) reported similar findings. The participants, six fathers, five of Caucasian origin and one Hispanic, of children with severe cerebral palsy received no support from family and community members. Likewise the mothers participating in Huang, Kellett and St John’s (2011) study in Taiwan experienced their sole primary caregiver as a burden they were unable to share with others. In contrast, mothers in the study conducted by Magrill-Evans, Darrah and Galambos (2011) reported that the participants, in their mixed method study, who were Canadian mothers of children with disability, felt they received physical support from significant others in their lives that increased over time as they needed. A critical analysis of the context of the above studies suggests that it is difficult to link receiving physical support with racial or ethnicity or geographical influences.

As a result of the high physical demands associated with caring for their children the participants in this study experienced musculoskeletal pain especially in the arms and waist. Other researchers reported similar findings. In Magrill-Evans, Darrah and Galambos' (2011) study, that explored the impact of the on-going caregiving role on mothers' physical, emotional, work and social well-being over a period of 7 to 9 years, participants complained of back and knee pain; in Nimbalkar et al.'s (2014) focus group discussion study, Indian mothers of children with cerebral palsy reported shoulder and back pain when carrying their children, and Geere et al., (2013) reported that participants' complained of chronic pain persisting for at least three months. Unfortunately none of these studies examine what the participants did about the pain. The physical demands of caring for children with disability including cerebral palsy can have a devastating effect on the general health of caregivers and caregivers who have health problems are unable to meet the demands of caregiving and the needs of the child.

#### **6.4.2 Financial demands**

According to the participants in this study caring for a child with cerebral palsy significantly added to their financial difficulties and most of them were underprivileged and lived in poor and miserable conditions. Wrigley- Asante (2008) conducted a mixed method study to investigate gendered poverty and survival strategies in the Dangme West District of Ghana and determined that there was a deplorable poverty level for both men and women in the district, but the women were poorer. The report indicated that "majority of the population live in small, scattered villages of less than 2000 people with poor infrastructure, poor road access and pipe-borne water only available in few larger

settlements”(p. 162). The study also revealed the high rate of male outmigration and women left behind to take care of the children as a traditional required responsibility. These findings echo the context of this study and support the findings that most of the fathers of children with cerebral palsy had left home. Few of the participants received financial support from the child’s father. It could be surmised that the fathers not only left home because of their children’s condition but also because it reflected a general attitude towards the roles of men and women in society.

Lack of money to provide for the basic needs of the child with cerebral palsy and other family members was a major concern for the participants, most of whom were women with sole responsibility for the family. and depended on occasional charity from friends and other family members but due to the high poverty level in the community this was difficult. Some depended on borrowing food for their children and staying hungry themselves while others ate the same food for weeks because it was less expensive. The situations and concerns expressed by the participants caused them considerable emotional stress. Ravallion (1992, cited in Engle and Black, 2008) in a World Bank Working Paper proposed this definition of poverty: “Economically poverty is typically based on income measures, with the absolute poverty line calculated as the food expenditure necessary to meet dietary recommendations, supplemented by a small allowance for non-food goods” (p. 243). This definition implies that the participants lived below the poverty line and this could have a serious negative impact on their children’s development, general health and well-being. Not surprisingly, poverty and financial hardship were identified as main concerns in a number of studies on caregivers of children with cerebral palsy, especially

those conducted in an African context (Hartley et al., 2005; Gona et al., 2010; McNally and Mannan, 2013). As in this study, the participants wished to work and earn an income to support their families but they had to give up their employment opportunities because of the difficulties of combining caring for their children and lack of support from others. Participants who did work to earn a living and cared for their child found combining these responsibilities difficult and stressful.

In this study, caregivers spent most of their limited financial resources on interventions that they hoped would improve their child's condition or result in their complete recovery. These interventions – primarily spiritual and herbal preparations – did not in reality result in any improvement in the child's condition or quality of life. In addition to paying for such interventions, caregivers had to spend extra money on transportation and specified items for the treatment. The participants described how they continued to pursue possible costly remedies even when these interventions were obviously not effective. The theme of constantly searching for a cure was particularly evident in the studies conducted in Africa and was associated with relatively huge expenditure on interventions and transportation (Hartley et al., 2005; Gona et al., 2010).

The phenomenon of 'seeking for healing' by Africans is associated with the deeply held belief that sickness can be attributed to spiritual origins (Farnes, Beckstrand, and Callister, 2011, p. 491). Farnes, Beckstrand, and Callister (2011) conducted an ethnographic study to examine the health seeking behaviours of Ghanaian childbearing women, and revealed that Ghanaian women with health problems normally turn to three systems of healing; biomedicine, ethno-medicine and faith. Participants in my study

identified two of these healing systems – ethno-medicine and faith healing. The narratives revealed caregivers accessed multiple sources of care simultaneously as they felt vulnerable to spiritual illness and as a result felt the need to seek spiritual protection. Farnes, Beckstrand, and Callister (2011) reported that participants in their study sought spiritual interventions for basically the same reasons. In addition to the above reason, participants in my study further indicated that they engaged in healer shopping due to lack of access to orthodox biomedicine, financial challenges, lack of understanding of the child's condition, and social influence. The healer shopping of ethno-medicine was more accessible to them and they felt that practitioners had a better understanding of cerebral palsy and provided more useful information. The term 'healer shopping' was first defined by Kroeger (1983) as "the use of multiple healers without referral from the first for a single episode of illness" (p. 147). The 'healer shopping' phenomenon is a common practice of individuals suffering from chronic illness in Africa including Ghana. de-Graft Aikins (2005) explored the evidence of 'healer shopping in Africa' from the practices of Ghanaians who had diabetes and found that although participants preferred biomedical management as an ideal health care practice compared to ethno-medical and faith healing, they were driven to cure seeking and faith healing due to the psychosocial impact of diabetes and high cost of biomedical treatment.

The World Health Organisation has recommended the bio-psychosocial model approach for the management of chronic disabling conditions (WHO, 2001). However due to the high incidence of communicable diseases, diseases of environmental degradation and pollution which outnumber chronic diseases as a cause of death, many African health

systems underestimate the importance of building human and material capacity for chronic disease care (de-Graft Akins et al., 2010) as well as adoption of the biopsychosocial model of health. Ghana, as a Sub-Saharan African country, has not yet developed management of chronic illness particularly implementation of rehabilitation programmes for people with disability (Tinney et al., 2007) especially children. As revealed in my study, the health clinics that the participants attended failed to address the biopsychosocial problems of cerebral palsy.

#### **6.4.3 Social influence**

Social influence was associated with the demands made by individuals in the community and the need for the caregivers to conform to society's expectations. Caregivers' acknowledged how their society influenced their efforts to find interventions to help their children and make decisions on their behalf, however, community members' expectations and attitudes often conflicted with their own personal beliefs and values. Trying to negotiate and manage this conflict caused the participants' considerable additional emotional distress. This consistent interference by the community members could be due to their perception that caregivers lack the capacity to adequately take care of their children and the caregivers' ability to identify and access appropriate help. A good society, according to Glenn (2000) is a society where those who cannot care for themselves are cared for and the offers of advice and counselling, described by the participants, could be based on good intentions and a genuine desire to benefit the child with disability. However, the participants frequently experienced what was offered as incorrect and, on occasion, harmful. Huang, Kellett and St John (2011) also reported the emotional impact,

experienced by the participants in their study, of receiving negative, inconsistent and potentially harmful information about cerebral palsy. Caregivers described their challenges in getting accurate formal information about cerebral palsy. They expressed feelings of anger and confusion about inconsistent information they received from the community members and in some cases health professionals.

The misinterpretation and inconsistent information of cerebral palsy in most countries in Africa is largely due to lack of trained personnel and medical knowledge and diagnostic facilities (Donald et al, 2015). The themes that emerged from Donald's report resonate with the findings of this study and include: high levels of social stigma toward children with cerebral palsy and their families, poverty and inability to provide the basic needs for the children, and the need to improve early detection of cerebral palsy and knowledge among medical practitioners. The first point of contact for children with cerebral palsy and their parents in Ghana are the district health clinics. However, those participants who had contacted the nearest health clinic found but the doctors unable to give them logical explanation and information about the condition.

## **6.5 Chapter summary**

The caregiving role of children with cerebral palsy who have not received any form of rehabilitation in a rural Ghanaian context was described under two main themes 'developing personal beliefs to support the caregiving role' and 'the demands that shape the experience of caring'. The ICF model can be used to describe the complex interaction between the impairment of cerebral palsy and the personal and environmental factors highlighted in this study. The meanings participants' ascribed to the caregiving role were

informed by a diversity of personal factors, including: age, educational background, ethnicity, personal beliefs and perceptions. The domain of environmental factors of the ICF was used to describe the context and the demands that shaped the caregiving role. The social model of disability was also integrated into the discussion of environmental factors. The Integrative Harmony Model (IHM) stresses the importance of caregivers being able to establish a balance of harmony between their strengths and the burden of caregiving. This model provides a useful framework for the struggles to develop strategies to support and balance the demands of caregiving that the participants' described.

The overarching theme of developing personal beliefs to support the caregiving role focused on caregivers' religious and spiritual beliefs and strategies that resulted in both positive and negative outcomes. From a positive perspective the participants were able to cope, were committed to caring supported by their religious beliefs, they accepted their children's condition and had hope for the future. They did, however, consistently articulate negative outcome of feelings of despair and sorrow. These negative effects could be attributed to lack of understanding of the condition, the attitude of family and community members and lack of formal, financial, physical and social support which inform the second main theme demands that shaped the caregiving role.

The meanings attributed to these experiences were grouped in three secondary themes: physical demands, financial demands and societal influence. The physical demands included physical burden associated with the responsibilities of physically assisting their children in activities of daily living. The delivery and demands of the caregiving task were exaggerated due to lack of competence and training, assistive devices,



and physical support from family members as well as the other social required responsibilities of the caregivers. These tasks resulted in caregivers' experiencing musculoskeletal, often chronic, pain. Caregivers in addition experienced financial difficulties due to the high cost of treatment interventions, lack of financial support, inability to work because of the demands of care and lack of reliable source of income. Societal influence complicated the caregiving role as caregivers had to conform to the dictates of the society, and deal with negative social attitudes like stigmatization and discrimination.

In the final chapter, I reviewed the study findings in relation to how it addressed the objectives set for this study. I also provided a summary of the study's contribution to knowledge, implications to physiotherapy and more broadly to rehabilitation practice. It also highlighted the implications for physiotherapy and rehabilitation education continuous professional development as well as plans for dissemination of the research findings.

## **Chapter 7**

### **Conclusion**

#### **7.1 Summary of the rational for using descriptive phenomenology**

This chapter presents a brief evaluation of the use of descriptive phenomenology as the most appropriate methodological choice for this study. The process of adhering to descriptive phenomenology was described in detail in Chapter 3: Methodology. In adopting a descriptive phenomenological approach to the research process, the study provided a novel invariant or essential structure that represents the core nature of the phenomenon of caring for a child with cerebral palsy in a Ghanaian context. Husserl's central premise that human experience is the fundamental source of knowledge and study and that descriptive phenomenology offered an approach to studying "things as they appear" (Dowling, 2007, p.132) guided me throughout the entire research process and enabled me to produce an authentic and transparent account of the experience that clearly reflected the 'voices' of the participants. To ensure the rigour of descriptive phenomenological research three major interlocking phases should be strictly adhered to according to Giorgi (1997), as quoted in Norlyk and Harder (2010), "First the researcher gathers detailed concrete description of specific experiences from others; secondly the researcher adopts the attitude of phenomenological reduction and finally searches for the essence of the experiences" (428).

Given that the Ghanaian context involved caregivers in rural communities who had no access to rehabilitation services, potential participants were initially difficult to locate and recruit into the study. Hence the use of purposive sampling was advantageous as it

gave the Community Health Nurses the mandate to assist the researcher in purposively recruiting the participants based on the established inclusion criteria. The descriptive phenomenological approach enabled me to justify the small sample size and an in-depth exploration with individuals – 12 caregivers of children with cerebral palsy in this study - who have the experience and personal knowledge of the phenomenon. However, due to the deplorable living conditions of the participants, coupled with their passion to find a solution for their children's condition, some participants censured what they told me about their experiences during the interviews, for example, by initially not revealing the practices, they perceived as 'bad,' involving access to spiritual interventions. To counteract this attitude I made every effort to achieve rapport with each participant before the interview, explained the nature and purpose of the study, and used probing questions. Furthermore, I incorporated other forms of data in the data analysis process including field notes, reflective diary entries, and member checking to promote the credibility of the interviews. The data collection procedure of this study - in-depth interviews - conformed to the Husserlian concept of descriptive phenomenology (Giorgi and Giorgi, 2003). The use of in- depth interviews was beneficial as I was able to explore and gather experiential narrative material that served as a resource for developing a richer and deeper understanding of the phenomenon of caring for a child with cerebral palsy in a rural Ghanaian context (Van Manen, 1990).

The central aim of descriptive phenomenology is to gain rich or 'thick' information that represents the essential nature of the individuals' experiences and that "communicates the sense and logic of the phenomenon to others" (Todres, 2005, p. 110). In this study, this meant I focused on the subjective accounts of the caregivers I interviewed not on the actual

experience itself. According to Englander (2012), in conducting descriptive phenomenology: “one seeks knowledge of the content of the experience, often in depth, to seek the meaning of a phenomenon, not ‘how many’ people who experienced such phenomenon” (p. 21). The notion of data saturation as a justification for the sample size in descriptive phenomenology is controversial and, given the difficulties experienced in accessing and recruiting participants, I did not claim that data saturation had been achieved. The complexity of the participants’ context and life situations did not allow me to continue the data collection process until such a time when new data did not yield any further new information about the phenomenon as recommended by some authors (Mason, 2010; Guest, Brunce and Johnson 2006). However, I felt that the rich data acquired was sufficient to form the essence of the phenomenon (invariant meaning) and, as recommended by Husserl, the process of imaginative free variation enabled me to develop and understand the essence of the phenomenon. The process of how free imaginative variation was implemented was described in detail in the methodology chapter (Section 3.7.2 under step 4).

The caregivers who participated in this study could be described as vulnerable in terms of their inability to read and write, their low level of education, and lack of knowledge about cerebral palsy. Hence a considerable power differential existed between the participants and me, a highly educated researcher who is also a physiotherapist. The tension or power imbalances that can arise due to differences in social class between the researcher and the researched have been discussed in the literature (for example, Finlay, 2000b). The use of reflexivity as a constituent of descriptive phenomenology addressed

this imbalance as discussed in detail in the Methodology Chapter, 3.6.3: Achieving reflexivity. To address this power imbalance I critically reflected on the values and beliefs I held about the phenomenon being studied. In order to achieve rapport and a degree of reciprocity I sometimes shared these with the participants during the interviews and I also made a conscious effort not to avoid developing a therapeutic relationship when the caregivers ask questions pertaining to their child's situation or cerebral palsy.

The principle of transparency is an important aspect of qualitative research in general and specifically in descriptive phenomenological research and required that I thoroughly describe and justify the entire research process. Frequent consultation with my supervisory team and engaging in a bracketing interview encouraged me to set aside, as much as possible, my internal beliefs, experiences, understandings, biases, judgments and assumptions about the study topic and authentically listen to the participants' perspectives and describe the essence of the phenomenon being studied. In writing this thesis, I provided information about my educational background, beliefs, values and attitudes associated with caring for a child with cerebral palsy, and the caregiving role and responsibilities. I maintained the rigour of this study, by ensuring that, at every stage, my decisions were made explicit and presented accurately and in detail. This was particularly important during the data collection and translation and transcription of the interviews. Ensuring transparency of the process and the role of the researcher allows readers to make their own evaluation of the credibility of the study.

Initially my relationship with the study participants was characterised by my emotional responses to their situations and concerns. I experienced conflict between my

desire to complete rigorous research in order to achieve my doctorate degree and my concerns as a clinical physiotherapist about the lack of rehabilitation services available to the participants. The first person I interviewed in the pilot study was a caregiver of a 14-year-old child with severe athetoid cerebral palsy. I found myself unable to hide my need to try to improve the well-being of the child and the caregiver in the caregiving role. I completed this interview but, before continuing with data collection, I looked for a sustainable intervention for this child. As a result, I developed a process by which the participants and their children were connected with a non-governmental organisation (NGO) outreach physiotherapy program after their involvement in the study had ended. This process is discussed in detail in the Methodology Chapter, 3.4.5.1: Principle of Beneficence.

## **7.2 A review of the research aim and objectives**

The main purpose of this study was to explore the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana, but who have not received any form of rehabilitation. Within the broader aim I hoped to achieve the following objectives:

To explore the experiences of primary caregivers of children with cerebral palsy

To understand how primary caregivers of children with cerebral palsy conceptualise cerebral palsy and disability

To identify fundamental concerns associated with supporting children with cerebral palsy

The new understanding and knowledge about caregiving and how the aims and objectives of this study were met are summarized in the next section.

### **7.2.1 Objective 1: To explore the experiences of primary caregivers of children with cerebral palsy**

This objective originated in my interest, as a clinical physiotherapist, in gaining a more in-depth understanding of how caregivers' experience their role of caring for children with cerebral palsy in order to assist health professionals to develop context tailored interventions for children with cerebral palsy in rural Ghana. The concepts of caregiving discussed in the literature focus on the provision of assistance or to perform for other person activities, which are necessary for survival, human functioning or social participation (WHO, 2001). This study contributes additional knowledge about how caregiving is experienced in complex rural contexts. The two main themes, that constitute the findings of this study, encapsulate the experience of caregiving and highlight the central importance of the caregivers' psychological interpretation of, and emotional responses to, their child's condition. A number of intrinsic factors, unique to each participants, that shaped the caregiving role: personal religious and spiritual beliefs, , acquired knowledge or insight about the condition of the care recipient, and caregivers' perceptions about the attitude of their society. The manifestation of the psychological response to the child's condition shaped the decisions caregivers' made on behalf of their children. Caregivers demonstrated their psychological responses in several forms. Firstly, in their seeking for interventions and engaging in practices that they perceived could positively influence the child's situation and recovery. Secondly, in their perception of the

standard of care they provided in terms of their commitment to caring, the rewards of caring, the nature of caring, coping, hope for the future, and acceptance of the child's condition. Lastly in the unrelenting feelings of despair and sorrow they felt related to their child's situation and future prospects. The experience of caregiving was framed and influenced by physical, financial and societal demands related to their own well-being, their lack of financial resources and support, and their need for support from others and managing the opinions and attitudes of others.

#### **7.2.2 Objective 2: To understand how primary caregivers of children with cerebral palsy conceptualise cerebral palsy and disability**

The Equity Act of Great Britain (2010) states that a person is defined as being disabled if “they have a physical or sensory impairment which has a substantial and long term adverse effect on their ability to carry out normal day to day activity”. This somewhat simplistic definition, although it can be applied to the condition of the children who were the focus of caring in this study, is general in nature and fails to capture the impact and complexity of living with a disability in the long term particularly in difficult environments such as rural Africa. Different models of disability conceptualise disability from different perspectives, for example, the individual or environmental or holistic perspective. The medical or individual model of disability considers that the problems or challenges associated with the disability reside in the individual, it is an individual deficit and emphasises their misfortune at ‘not being normal’, not being the same as the majority, and not being ‘able bodied’(Shakespeare. 2006, p.220). Oliver (1998) highlighted that such



an individual model considers that functional limitations arise naturally from individual impairments and inabilities. The caregivers considered their children as severely disadvantaged in terms of competing and participating in social situations and negatively compared their children with cerebral palsy with ‘normal’ children and inferred that their children needed recovery often by spiritual interventions. The participants’ mostly defined their children with disability as being ‘sick’, unable to do anything for themselves or participate in social activities or lead a ‘normal life’. They experienced feelings of chronic sorrow for their children who ‘suffered’ from the condition. In the absence of appropriate medical or rehabilitation services the caregivers involved in this study sought commonly available alternative spiritual interventions.

### **7.2.3 Objective 3: To identify fundamental concerns associated with supporting children with cerebral palsy**

The fundamental concerns of the participants associated with caring for their children with cerebral palsy were integrated throughout both main themes and I found the Community Based Rehabilitation (CBR) Matrix (Motsch, 2008) useful as framework to discuss these concerns. According to Motsch (2008), the aim of CBR was to ensure that rehabilitation services are provided to all people with disabilities and their families, whether they live in urban or rural settings and whether rich or poor” (p. 18). The CBR Matrix framework considers five key components - Health, Education, Livelihood, Social, and Empowerment – and each are divided into five sub-domains. The concerns raised by the participants are discussed in terms of each key component.

The fundamental concerns associated with supporting children with cerebral palsy under the health component revealed issues related to health promotion and illness prevention, medical care, rehabilitation services and the use of assistive devices. The major concern was the lack of awareness about cerebral palsy. This concern is significant for the caregivers and also for the health care professionals who provide medical and rehabilitation services. The study findings revealed a paucity and lack of reliable information available for caregivers in rural areas and amongst members of rural communities about the prevalence and cause of cerebral palsy, the clinical presentation and management of the condition and among the public and also suggest a lack of expertise among some health professionals. Therefore, there is a need for health professionals, in particular the core rehabilitation professionals, to intensify the availability of accessible public education programmes focused on paediatric neurological conditions.

Secondly, the children with cerebral palsy of caregivers recruited for this study were officially diagnosed as having cerebral palsy only as a result of being identified as potential participants in this study. The age range of these children was 2 years 9 months to 14 years. Early diagnosis is considered important as it informs early and appropriate intervention. According to Ziviani et al. (2014), early intervention for children with physical disability can enhance child developmental outcomes, improve caregivers' ability to care for their children in the context of their own needs and increase family quality of life. Palmer (2004) suggested that neurological examination and measurement of milestone performance of children above 6 months old is sensitive enough to early detect motor abnormalities. These options were not available for the participants in this study.

Thirdly, caregivers expressed concerns about the lack of care they received during pregnancy and labour as this could have prevented their children from developing cerebral palsy or facilitated early diagnosis. The major concerns that participants raised related to poor nutrition and prolonged labour. Finally, health concerns were raised about the lack of training and advice about the physical aspects of caring for their children, that is, moving, positioning and transporting, and the child's and their own safety. Also none of the caregivers interviewed had access to assistive devices that could support them in these physical aspects of care and stimulate the child's motor development.

In relation to the matrix component of education, none of the children with cerebral palsy attended school and the majority of the caregivers were illiterate. In terms of livelihood, the majority of the participants were unemployed, were experiencing financial difficulties and had to rely on unreliable and inconsistent funding sources. The social component of the participants' experiences focused on the pressure they felt from family and other members of the community to comply with recommended spiritual interventions. Many of them described experiencing stigmatisation and discrimination from community members and within their society. A major concern was the lack of physical and financial support from family members and spouses. It was evident that there were no social or child protection measures in place as both caregivers and children with cerebral palsy experienced different levels of abuses associated with the society. Interestingly, the participants rarely described any relationships or circumstances that could be considered empowering. None of them admitted to receiving any government support (not readily available in any situation in the Ghanaian health care system), had any formal training to support their caregiver role, or belonged to any self-help groups. In addition, while all the

caregivers cherished strong spiritual and religious beliefs that influenced their intervention seeking activities, these did not seem to represent a sense of empowerment.

#### **7.4. Implications for physiotherapy and, more broadly, rehabilitation practices**

In this study the participants' perceptions of disability could be described in terms of the individual or medical model of disability and characterised by the assumption that the problems experienced by their children would disappear if a cure could simply be found. Caregivers described cerebral palsy as a sickness that required a cure. The implication of these perceptions is that caregivers' view health professionals as having expert knowledge and the services they deliver the capability of 'fixing' or resolving the problems they and their children experienced. In this type of health delivery system the person with a disability and their caregivers are frequently characterised as passive recipients of medical care. Hence, physiotherapy practitioners, similar to other health care disciplines, are at risk of enacting the phenomenon labelled the 'medicalization of disability'. One participant described this practice, in relation to the doctor in the hospital she consulted, as prescribing 'Polly pills' with the implication that these would cure the child's condition. Roush and Sharby (2011) suggest that "health care professionals' views of having an impairment are typically consistent with views held by the general population" (p.1719)

It is therefore important that health care providers view disability, not through a biomedical lens but instead take a more comprehensive approach, such as, the biopsychosocial model represents. Qualitative research, like this study, reveal the complex inter-relationship between the impairment, the environment and personal factors that a

biomedical focus negates. In addition, physiotherapists are encouraged to more specifically adopt the ICF framework (WHO, 2001) to assist in assessment, planning interventions, and evaluating progress with persons with disability.

Health care providers must make the shift from the current focus on educating the public about communicable disease (de-Graft Akins et al., 2010) and develop the skills to address the information needs of people with disability and their caregivers. Access to information in accessible and relevant forms leads to a better understanding about health conditions, the options for care and the individual role in prevention and self-management (Sykes, 2008, p.113). Easy to read and pictorial leaflets should be developed and made available to families and individuals living with disability. Caregivers who participated in this study consistently voiced the need for information about their children's condition and to support caregiving. Increased knowledge about cerebral palsy would promote intervention adherence, decrease misconceptions and the healer-seeking behaviours described by the participants and in the literature.

Physiotherapy and other health professional services for children with cerebral palsy in Ghana need to be administered, whether by an institution, outreach or community basis, through a Family Centred Services (FCS) approach. The family centred model recognizes the family, especially the caregivers, as experts in the care of their own children (Law et al., 2007) and tailors the services offered to meet the unique needs of each family. The family is in the position to give primary support to the child and is potentially in contact with the child with chronic condition from infancy to adulthood. Interventions directed at families have been linked to significant outcomes in child development (King et al., 2004; Rosenbaum, 2004). Hence future development of intervention for children with

cerebral palsy in the rural communities should consider the entire family system right from the planning stages so that the family can assume the responsibility of a major stakeholder. The FCS model identifies parents as resourceful partners in the provision of services for children with special needs and because parenthood is dynamic it continues to redefine the role of therapist and other health care professionals (Dirks and Hadders-Algra, 2011). Family centred service emerged from the concept that child rearing is a family affair and is informed by parents' attitudes, culture and values (Dirks and Hadders-Algra, 2011). Therefore FSC is made up of a combination of values, attitudes and beliefs that aim to empower children with special needs and their families (Rosenbaum, 2011). This study therefore provides a little knowledge on the attitude and beliefs of caregivers of children with cerebral palsy. Participation of the family is pivotal in ensuring appropriate rehabilitation services for their `child, which provides them with adequate and timely information and support (Redmond and Parrish, 2008; Harbourne, 2010).

Another implication of the study findings for physiotherapy practice relate to negative beliefs and attitudes about living with a disability of caregivers, other family members and the community. Klooster et al. ( 2009) opined that having positive social experiences with persons with disability in the capacity of a personal friend or a family member results in a higher regard for those with impairments than those who do not have contact. Health care professionals including physiotherapists must create more opportunities of interacting with people who have different levels of challenges and who are perceived to be different from others ( Roush & Sharby, 2011). Such an opportunity would be in organising the forum which could be a form of *durbur*, an atmosphere of reflecting on the people present feelings about disability could be created. In Ghana most

public health education and other health activities take place at traditional durbars. “Community ‘durbars’ are traditional gatherings comprised of drumming, dancing, speechmaking and public debate” (Nyonator et al., 2005, p. 27) Nyonator et al.,(2005) confirms the feasibility and the efficacy of open discussion of Community Health Planning and Services (CHPS) activities during durbars. Health care professionals employed to work in the district communities need to be encouraged to develop strategies by which they could sensitise and influence individual communities about inclusion of people with disability in general and about specific conditions such as cerebral palsy. Caregivers in this study changed their perceptions of disability as a result of giving birth to a child with cerebral palsy or caring for one. If provided with accurate and meaningful information and supported by relevant health care professionals such caregivers could be empowered to be advocates for their children, and people with disabilities in general, within their communities. This idea of enculturation and change effected by personal contact and involvement with people with disability is important not just in relation to caregivers but also health professionals. Health care professionals need to be encouraged through continuing professional education initiatives and their respective training programmes, to examine the values and beliefs they hold about disability, and create more social and positive contacts with people with disability, in order that they might change negative cultural values.

Within the Ghanaian context, although prevention, early detection and intervention programmes on childhood disabilities are ongoing in the various tertiary health institutions, there is limited information available about the extent of the early detection and intervention services for children with disabilities needed in rural communities. This

study highlights that children with cerebral palsy living in rural contexts are not detected early enough and they are currently unable to access appropriate services. Rehabilitation professionals in regional and district hospitals where rehabilitation services are accessible need to develop basic programmes that could routinely assess children, detect problems early, provide basic caregiver training and recommend evidence based interventions at the communities in their catchment areas. These programmes could be organised in collaboration with the Community Health Nurses at the Community Health Planning and Services (CHPS) compounds to incorporate multidisciplinary screening into their already existing school and child welfare clinics. Such programmes are the key to achieving good outcomes especially for children with cerebral palsy.

This study highlights the reality of current health care in Ghana where no child protection policies are implemented or health interventions specifically for children with cerebral palsy are offered in rural communities. Physiotherapist and other rehabilitation professionals working in the Ministry of Health need to make this a priority along the lines of the United Nations Convention on the Rights of the Child (UNCRC). Ghana was the first African country to endorse UNCRC in 1990 (Appiah, 2006) but still faces the challenges of implementing these policies effectively enough to make a difference to the lives of children with different forms of disability. Equal accessibility and free provision of rehabilitation services and of assistive devices are all enshrined in the disability rights legislation in Ghana under the Commonwealth Human Rights Initiative (CHRI, 2007). The Under Five Child Health Policy (2007-2015) developed by Ghana's Ministry of Health (MOH) of Ghana states that: "The Child Health Programme will advocate for



collection and use of appropriate data in planning interventions to address the management of children with existing long term mental and physical disabilities from malformations, birth trauma and other factors needs improvement”(Point 8 p.15). In 2016 children with cerebral palsy in the rural communities in Ghana have still not benefited from the implementation of this policy and, based on the study findings, implementation is strongly recommended. Report with the recommendations will be sent to the Ministry of Health and arrange for a presentation of the findings in the quarterly meeting with Public Health Regional representative meetings in capital city.

The central importance and influence of the caregivers’ strong spiritual and religious beliefs revealed in this study represent personal and environmental factors of significance physiotherapy or rehabilitation practice that influence health behaviour and decisions. Health professionals’, particularly if encouraged to adopt a biopsychosocial approach to their practice, need to take into account and understand clients’ spiritual and religious beliefs. Rehabilitation professionals, as individuals, have their own beliefs and values that they bring into their clinical work. As Roush and Sharby (2011) suggest: “therapists do not always choose the values they bring to the clinical setting, many of which are the result of living in a culture with an ableist orientation” (p. 1721). It is worth noting that in conducting this study, I had to bring into consciousness through self-reflections, the beliefs, values and biases I had developed throughout my childhood and adult life about living with a disability and the concept of care so that I could ‘bracket’ these and fully understand, without judgment, the caregivers’ experiences. Roush and Sharby (2011) further recommend that health professions should “carefully evaluate any

biases that may interfere with their full collaboration with a client or consumer to meet his or her participation goals” (1721).

Caregivers in this study offered advice to health care professionals, such as: “I think most women with children with CP may need a clinical psychologist, because caring for a child with CP is very stressful. We go through a lot of emotional stress, we really need counselling” ( participant Eno). The family centred approach increasingly adopted in paediatric rehabilitation services usually involves the input of an interdisciplinary team. The multiple co-morbidities associated with cerebral palsy require the support from all disciplines at all levels of health care. The primary health component of Ghana’s health system is currently offering several community programmes on the prevention of communicable diseases. It would be relatively easy for rehabilitation professionals to ‘piggy back’ on these initiatives and offer a similar programme focusing on basic knowledge and skills needed to support a child with disability in the community. Physiotherapists at the regional level should be encouraged to develop and contribute to the delivery of such community rehabilitation programmes. The ongoing physiotherapy outreach programme is being organised by the Community Health Nurses. Further deliberation is needed with all the stakeholders on the sustainability of the programme, as the NGO is funding for the logistics and allowances for the physiotherapist.

## **7.5 Implications for physiotherapy education and continuing rehabilitation professional education**

“Understanding personal beliefs and biases is the first order of cultural competence and requires significant, intentional self-reflection and guidance” (Roush & Sharby, 2011,

p.1721). However, these are not skills that come naturally to health care students or health professionals. It is essential that the skills of reflexivity I have incorporated into conducting this research are integrated into the professional education curriculum and related to rehabilitation practice not just for physiotherapy students but other professionals involved in rehabilitation teams, for example, occupational therapy, and speech therapy. This requires instructors to value such curricular content and consciously guide the acquisition of these skills by the students. Continuing professional education courses are most commonly offered for specific disciplines, however, courses that involve multiple related disciplines with a rehabilitation theme would encourage an interdisciplinary team approach and support adoption of the family centred approach to children's health services. Special attention should be given to courses that develop strategies, based on research evidence, with the aim of promoting the quality of life of caregivers and children with cerebral palsy. Child protection and rights issues as well as disability studies should be incorporated into the further education of rehabilitation professionals. All education institutions should promote awareness of and advocate for new and existing opportunities to provide formal and informal support for children with disability and their families.

## **7.6 Implication to health policy**

A brief summary of the work already done with the Ghana Health Service since the year 2012 is provided in the table 6.1. My motivation of providing this section is to provide my readers with some ongoing activities which had served as a solid foundation for the implementation of the recommendations of this study. It is also in line with the recommendations made by Naami (2014) that "Decision makers need to be persuaded to

make additional policies and /or enforce existing ones, to promote the inclusion and effective participation of persons with disabilities in the society” (p.21).

**Table 7.1 A brief report of work done with the Ghana Health Services GHS**

Two meetings were held with the Directorate of Child Health in the Ghana Health Service to explore the GHS positions on prevention, early detection and intervention of childhood disability. The first meeting highlighted the significance of early detection and intervention of childhood disability. The directors acknowledged the increasing prevalence rate in childhood disability, which they presumed might be associated with improved maternal and neonatal care in Ghana. They were also of the view that children who are at risk of developing disability are now surviving due to the improved care. Thus the importance of including ‘Early detection and Prevention of Childhood Disability’ within existing policies and strategies is recognized as an urgent need. Based on this identified need, GHS requested CBM (Non-Governmental Organisation) in conjunction with School of Bio-medical and Allied Health Science (University of Ghana) to develop some information sheets to facilitate early detection of neo-natal impairment, which can be used by Midwives. The information was to be included in the New-born assessment booklet.

During the second Meeting the first draft of information on early detection was presented on a double-sided A4 sheet and was well received by GHS. However, it may need a review prior to publication.

During the meetings the following themes emerged

1. Include Prevention of Childhood disability components within the planned GHS workshops for midwives and CHN using CBMs material and the developed leaflet. This can be part of the newly introduced maternal & neo-natal training package.  
( Document near completion)
2. Start sensitizing the department responsible for the development of Child Health records to include/revise the screening methods for childhood

impairments as part of the next child health record book that is due for review in 2013 (accomplished).

The findings of the pilot study of this current study was used as the basis of advocating for the nurses to be equipped to train caregivers of children with physical disabilities with basic handling techniques and the use of local materials to stimulate motor development of the children. There was also a strong argument on the need for Nurses to champion the sensitization of the public on inclusive childhood development and positive attitude towards persons with disability and their families.

(More children with different forms of disability are being identified in the communities)

3. SAHS and CBMs expertise (cross cutting all disabilities) can be used during this review process. ( **Gifty Nyante** was involved)
4. As the CHNs' and appropriate staff continue to sensitize the community on childhood disabilities, the information could gradually be integrated at an earlier stage in pregnancy as primary prevention message.

( Sensitization messages ongoing in the various communities)

5. Basic training of CHNs and CHIPs compound health workers on early detection, handling and basic stimulation of children with cerebral palsy.

(A. A work shop was organised for the training of 48 qualified Community Health Nurses on community intervention of cerebral palsy, the practical use of the primary health care manual, the use of the birth impairment manual and early detection after birth.

(B. The sensitization influenced the recommendation for the Nurses and Midwifery Council of Ghana to include prevention, early detection and early intervention, basic handling and community intervention skills included in the revised curriculum of all the six basic programmes in Nursing in 2015 ( Registered General Nursing, Registered Midwifery, Registered Community Health Nurses, Registered Mental Health Nurses, Health Assistance preventive and curative).

## **7.7 Dissemination of research findings.**

The dissemination of the preliminary research findings began after the pilot study was conducted when two children with severe cerebral palsy who were not receiving any form of rehabilitation were identified. The District Health Directorate was informed about the collaboration of a nongovernmental organisation (NGO) I established and the NGO's intention to establish outreach physiotherapy services for the caregivers recruited in the study and their children. I provided an informal but frequent research update to the District Health Director of Shua-oshodoku District and a cross section of Community Health Nurses who were continuing to identify potential caregivers in their respective catchment areas to participate in the study who might also benefit from the outreach physiotherapy programme. The caregivers only become involved with the outreach programme once they had contributed to the study. However the caregivers were informed that taking part of the study was voluntary and it would not serve as a prerequisite for receiving intervention for their children in the outreach physiotherapy programme. An interim report of the research process was submitted to the Ghana Health Services Ethics Committee as a requirement of the ethics approval process.

Findings of the study were presented to a group of about 98 participants consisting of 2 Nursing Tutors from all the public and private Nursing Training Institutions in the Northern and Middle zones of Ghana in June 2016. The southern zone training is scheduled to take place in November. The training workshop was on prevention, early detection and early intervention, basic handling and community intervention skills included in the revised curriculum of the various Nursing Training programmes. Being the

main facilitator of the workshop to train the Tutors, I took the advantage to disseminate the results of my findings to buttress the need for the training and the inclusion of the information in the curriculum.

Plans for further dissemination of the study findings include an initial submission, aimed at professionals developing rehabilitation programmes for children with cerebral palsy, for publication in the *African Journal for Physiotherapy and Rehabilitation Sciences* as this focuses on rehabilitation issues in Africa and a second article in an international rehabilitation journal. The study findings will be presented at the next Ghana Physiotherapy Association Meeting and University of Ghana College of Health Sciences Conference in March and September 2017 respectively.

#### **7.7 Direction for future research**

The study findings suggest the need for a survey at the District health administration level in Ghana to accurately identify children with cerebral palsy, their life circumstances and rehabilitation needs. This could be based on the door-to-door cross sectional survey study conducted by El-Tallawy et al. (2011) to screen the total population of children in El-Kharga district in Egypt for impairments associated with cerebral palsy. The first stage of this study used a simple questionnaire to identify children with neurological conditions including cerebral palsy, after which a comprehensive neurological examination was performed to assess the impairments associated with cerebral palsy. Based on my reading of the literature and my professional experience I highly recommend that any survey study that is conducted should be followed by an intervention. No

intervention no survey research! In the methodology chapter I discussed in some detail an outreach physiotherapy programme offered by an associated NGO for children with cerebral palsy. Rigorous research is needed to ascertain the programme's effectiveness and sustainability. Finally, the participants' experiences and perceptions of the short and long term effects of the outreach physiotherapy programme they became engaged with after completion of the study should be explored.



## References

- Adams, K., Hean, S., Sturgis, P., and Clark, J. M. (2006) 'Investigating the Factors Influencing Professional Identity of First-Year Health and Social Care Students'. *Learning in Health & Social Care* 5 (2), 55-68
- Addo, E. O. (1997) *Kwaku Nkrumah: A Case Study of Religion and Politics in Ghana.*: University Press of America
- Ahern, K. J. (1999) 'Ten Tips for Reflexive Bracketing'. *Qualitative Health Research* 9 (3), 407-411
- Allen, D. (2004) 'Ethnomethodological Insights into insider–outsider Relationships in Nursing Ethnographies of Healthcare Settings'. *Nursing Inquiry* 11 (1), 14-24
- Ando, N. and Ueda, S. (2000) 'Functional Deterioration in Adults with Cerebral Palsy'. *Clinical Rehabilitation* 14 (3), 300-306
- Ann, Ö., Hagg, K., and Dahlgren, L. (1999) 'Competent Women and Competing Professions-Physiotherapy Educators' Perceptions of the Field'. *Advances in Physiotherapy* 1 (2), 59-72
- Anttila, H., Autti-Ramo, I., Suoranta, J., Makela, M., and Malmivaara, A. (2008) 'Effectiveness of Physical Therapy Interventions for Children with Cerebral Palsy: A Systematic Review'. *BMC Pediatrics* 8, 14-2431-8-14
- Appelbaum, M. G. and Smolowitz, J. L. (2007) “Appreciating Life: Being the Father of a Child with Severe Cerebral Palsy” *Journal of Neuroscience Nursing* 44.1, 36-42
- Appelbaum, M. G. and Smolowitz, J. L. (2012) 'Appreciating Life: Being the Father of a Child with Severe Cerebral Palsy'. *The Journal of Neuroscience Nursing : Journal of the American Association of Neuroscience Nurses* 44 (1), 36-42
- Arber, A. (2006) 'Reflexivity A Challenge for the Researcher as Practitioner?'. *Journal of Research in Nursing* 11 (2), 147-157
- Arnadottir, U. and Egilson, S. T. (2012) 'Evaluation of Therapy Services with the Measure of Processes of Care (MPOC-20): The Perspectives of Icelandic Parents of Children with Physical Disability'. *Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community* 16 (1), 62-74
- Aron, L. (2000) 'Self-Reflexivity and the Therapeutic Action of Psychoanalysis.'. *Psychoanalytic Psychology* 17 (4), 667
- Aslam, M. and Kingdon, G. G. (2012) 'Parental Education and Child health—

understanding the Pathways of Impact in Pakistan'. *World Development* 40 (10), 2014-2032

Bailes, A. F. and Succop, P. (2012) 'Factors Associated with Physical Therapy Services Received for Individuals with Cerebral Palsy in an Outpatient Pediatric Medical Setting'. *Physical Therapy* 92 (11), 1411

Baker, S. E., and Edwards, R. (2012) How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research. Southampton: ESRC National Centre for Research Methods, University of Southampton. Available online: [http://eprints.ncrm.ac.uk/2273/4/how\\_many\\_interviews.pdf](http://eprints.ncrm.ac.uk/2273/4/how_many_interviews.pdf) Accessed on 22nd July 2015

Banister, P., Bunn, G., Burman, E., and Daniels, J. (2011) *Qualitative Methods in Psychology: A Research Guide: A Research Guide.*: McGraw-Hill International

Barton, L. (1996) *Disability and Society: Emerging Issues and Insights.*: Longman Group United Kingdom

Beauchamp, T., Childress, J. (2001). *Principles of Biomedical Ethics*, 5th ed. Oxford University Press Inc., Oxford

Bednall, J. (2006) 'Epoche and Bracketing within the Phenomenological Paradigm'. *Issues in Educational Research* 16 (2), 123-138

Bellah, R. N. (2006) 'Flaws in the Protestant Code: Theological Roots of American Individualism'. *The Robert Bellah Reader*, 225-245

Benjamin F. Crabtree and William L. Miller (1999) *Doing Qualitative Research.*: Sage

Bigbee, J.L. and Lind, B., 2007. Methodological challenges in rural and frontier nursing research. *Applied Nursing Research*, 20(2), pp.104-106.

Birbili, M. (2000) 'Translating from One Language to another'. *Social Research Update* 31 (1)

Bird, C. M. (2005) 'How I Stopped Dreading and Learned to Love Transcription'. *Qualitative Inquiry* 11 (2), 226-248

Biritwum, R. B., Devres, J. P., Ofosu-Amaah, S., Marfo, C., and Essah, E. R. (2001) 'Prevalence of Children with Disabilities in Central Region, Ghana'. *West African Journal of Medicine* 20 (3), 249-255

Blaikie, N. (2007) *Approaches to Social Enquiry: Advancing Knowledge.*: Polity press Uk

- BOBATH, K. and BOBATH, B. (1952) 'A Treatment of Cerebral Palsy Based on the Analysis of the Patient's Motor Behavior'. *The British Journal of Physical Medicine* : Including its Application to Industry 15 (5), 107-117
- Borg, J., Lindstrom, A., and Larsson, S. (2009) 'Assistive Technology in Developing Countries: National and International Responsibilities to Implement the Convention on the Rights of Persons with Disabilities'. *Lancet (London, England)* 374 (9704), 1863-1865
- Bourke-Taylor, H., Howie, L., and Law, M. (2010) 'Impact of Caring for a school-aged Child with a Disability: Understanding Mothers' Perspectives'. *Australian Occupational Therapy Journal* 57 (2), 127-136
- Bowen, G. A. (2008) 'Naturalistic Inquiry and the Saturation Concept: A Research Note'. *Qualitative Research* 8 (1), 137-152
- Bower, E., Michell, D., Burnett, M., Campbell, M., and McLellan, D. (2001) 'Randomized Controlled Trial of Physiotherapy in 56 Children with Cerebral Palsy Followed for 18 Months'. *Developmental Medicine & Child Neurology* 43 (1), 4-15
- Bower, E., Michell, D., Burnett, M., Campbell, M., and McLellan, D. (2001) 'Randomized Controlled Trial of Physiotherapy in 56 Children with Cerebral Palsy Followed for 18 Months'. *Developmental Medicine & Child Neurology* 43 (1), 4-15
- Bradbury-Jones, C., Sambrook, S., and Irvine, F. (2009) 'The Phenomenological Focus Group: An Oxymoron?'. *Journal of Advanced Nursing* 65 (3), 663-67
- Bray, A., Moss, J., Forrester, K., and McConnochie, K. (2005) 'Evaluation of the Complex Carers Group Project'. *Dunedin, Donald Beasley Institute Online* Available at <http://www.carersair.net.nz/sites/default/files/documents/CCG%20Evaluation%20Report.pdf> Accessed on 30<sup>th</sup> May 2016
- Britten, N. (1995) 'Qualitative Interviews in Medical Research'. *BMJ (Clinical Research Ed.)* 311 (6999), 251-253
- Bromer, J. and Henly, J. R. (2004) 'Child Care as Family Support: Caregiving Practices Across Child Care Providers'. *Children and Youth Services Review* 26 (10), 941-964
- Brotherson, M. J., Cook, C. C., Erwin, E. J., and Weigel, C. J. (2008) 'Understanding Self-Determination and Families of Young Children with Disabilities in Home Environments'. *Journal of Early Intervention* 31 (1), 22-43
- Brown, G. T. and Burns, S. A. (2001) 'The Efficacy of Neurodevelopmental Treatment in Paediatrics: A Systematic Review'. *The British Journal of Occupational Therapy* 64 (5), 235-244

- Buck, D. S., Rochon, D., Davidson, H., McCurdy, S., and Committee of Helthcare for the Homeless--Houston (HHH) (2004) 'Involving Homeless Persons in the Leadership of a Health Care Organization'. *Qualitative Health Research* 14 (4), 513-525
- Burkhard, A. (2013) 'A Different Life: Caring for an Adolescent Or Young Adult with Severe Cerebral Palsy'. *Journal of Pediatric Nursing* 28 (4), 357-363
- Burkhard, A. (2013) 'A Different Life: Caring for an Adolescent Or Young Adult with Severe Cerebral Palsy'. *Journal of Pediatric Nursing* 28 (4), 357-363
- Burkhard, A. M. (2011) 'The Lived Experience of Mothers Caring for an Adolescent or Young Adult with Severe Cerebral Palsy' *Degree awarded: Ph.D. Nursing. The Catholic University of America.* Available online [http://aladinrc.wrlc.org/bitstream/handle/1961/9709/Burkhard\\_cua\\_0043A\\_10220display.pdf?sequence=1](http://aladinrc.wrlc.org/bitstream/handle/1961/9709/Burkhard_cua_0043A_10220display.pdf?sequence=1) (Accessed on 18<sup>th</sup> November. 2015)
- Burtner, P., Woollacott, M., Craft, G., and Roncesvalles, M. (2007) 'The Capacity to Adapt to Changing Balance Threats: A Comparison of Children with Cerebral Palsy and Typically Developing Children'. *Developmental Neurorehabilitation* 10 (3), 249-260
- Butler, C. and Darrah, J. (2001) 'Effects of Neurodevelopmental Treatment (NDT) for Cerebral Palsy: An AACPDm Evidence Report'. *Developmental Medicine and Child Neurology* 43 (11), 778-90
- Byrne, M. B., Hurley, D. A., Daly, L., and Cunningham, C. G. (2010) 'Health Status of Caregivers of Children with Cerebral Palsy'. *Child: Care, Health & Development* 36 (5), 696-702
- Caelli, K. (2000) 'The Changing Face of Phenomenological Research: Traditional and American Phenomenology in Nursing'. *Qualitative Health Research* 10 (3), 366-377
- Cahan, E. and Bromer, J. (2003) 'Trends in the History of Child Care and Family Support: 1940–1996'. *Long-Term Trends in the Well-being of Children and Youth, CWLA Press, the University of Illinois at Chicago Series on Children and Youth, Washington, DC*, 207-228
- Cans, C. (2000) 'Surveillance of Cerebral Palsy in Europe: A Collaboration of Cerebral Palsy Surveys and Registers'. *Developmental Medicine & Child Neurology* 42 (12), 816-824
- Carona, C., Pereira, M., Moreira, H., Silva, N., and Canavarro, M. C. (2013) 'The Disability Paradox Revisited: Quality of Life and Family Caregiving in Pediatric Cerebral Palsy'. *Journal of Child and Family Studies* 22 (7), 971-986
- Carpenter, C. (1994) 'The Experience of Spinal Cord Injury: The Individual's Perspective--Implications for Rehabilitation Practice'. *Physical Therapy* 74 (7), 614-28; discussion 628-9

Carpenter, C. (1997) 'Conducting Qualitative Research in Physiotherapy: A Methodological Example'. *Physiotherapy* 83 (10), 547-552

Carpenter, C. (2013). Phenomenology and Rehabilitation Research. In: P. Liamputtong (Ed). *Research Methods in Health: Foundations for Evidence-Based Practice* (2<sup>nd</sup> edn, pp 115-131) Melbourne: Oxford University Press / Medical Sciences International.

Carpenter, C. and Suto, M. (2008) *Qualitative Research for Occupational and Physical Therapists: A Practical Guide*: Blackwell

Cerebral Palsy Africa (2014) Available online <http://www.cerebralpalsyafrika.org/Ghana.htm>

Charmaz, Kathy (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.

Chen, C. P. (2001) 'On Exploring Meanings: Combining Humanistic and Career Psychology Theories in Counselling'. *Counselling Psychology Quarterly* 14 (4), 317-330

Chen, H. and Boore, J. R. (2010) 'Translation and back-translation in Qualitative Nursing Research: Methodological Review'. *Journal of Clinical Nursing* 19 (1-2), 234-239

Cho, E. (2007) 'A Proposed Theoretical Framework Addressing the Effects of Informal Caregivers on Health-Related Outcomes of Elderly Recipients in Home Health Care'. *Asian Nursing Research* 1 (1), 23-34

Christiansen, A. S. and Lange, C. (2008) 'Intermittent Versus Continuous Physiotherapy in Children with Cerebral Palsy'. *Developmental Medicine & Child Neurology* 50 (4), 290-293

Clark, D. (1997) 'What is Qualitative Research and what can it Contribute to Palliative Care?'. *Palliative Medicine* 11 (2), 159-166

Colaizzi, P. F. (1978) Psychological research as the phenomenologist views it. In: Valle R. S. King, M. (eds) *Existential phenomenological alternatives for psychology*. Oxford University Press, New York

Collier, D. (1995) 'Translating Quantitative Methods for Qualitative Researchers: The Case of Selection Bias'. *American Political Science Review* 89 (02), 461-466

Copley, M. F. and Bodensteiner, J. B. (1987) 'Chronic Sorrow in Families of Disabled Children'. *Journal of Child Neurology* 2 (1), 67-70

Coulon, A. (1995) *Ethnomethodology: Qualitative Research Methods* London Sage

- Creswell, J. Hanson, W.E, Clark V.L.P & Morales, A (2007) Qualitative research designs: selection and implementation. *The counselling Psychologist*, 35(2): 236-264
- Creswell, J. W. (2007) 'Qualitative Inquiry and Research Design: Choosing among Five Approaches .' 2nd ed. Thousand Oaks, CA: Sage
- Creswell, J. W. and Clark, V. L. P. (2007) *Designing and Conducting Mixed Methods Research.*: Wiley Online Library
- Creswell, John (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: Sage
- Crossan, F. (2003). Research philosophy: towards an understanding. *Nurse researcher*, 11(1), 46-55.
- Crotty, M. (1998) *The Foundations of Social Research: Meaning and Perspective in the Research Process.*: Sage
- Dalvand, H., Hosseini, S. A., Rassafiani, M., Samadi, S. A., Khankeh, H. R., and Kelly, G. (2015) 'Co-Occupations: The Caregiving Challenges of Mothers of Children with Cerebral Palsy'. *British Journal of Occupational Therapy*, 5 (1), 1-10
- Damiano, D. L., Dodd, K., and Taylor, N. F. (2002) 'Should we be Testing and Training Muscle Strength in Cerebral Palsy?'. *Developmental Medicine & Child Neurology* 44 (01), 68-72
- Dansecu, E. R. (1997) 'Parental Beliefs on Childhood Disability: Insights on Culture, Child Development and Intervention'. *International Journal of Disability, Development and Education* 44 (1), 41-52
- de-Graft Aikins, A. (2005) 'Healer Shopping in Africa: New Evidence from Rural-Urban Qualitative Study of Ghanaian Diabetes Experiences'. *BMJ (Clinical Research Ed.)* 331 (7519), 737
- Denham, A. R., Adongo, P. B., Freyberg, N., and Hodgson, A. (2010) 'Chasing Spirits: Clarifying the Spirit Child Phenomenon and Infanticide in Northern Ghana'. *Social Science & Medicine* 71 (3), 608-615
- Denzin, N. K. and Lincoln, Y. S. (2005) *The SAGE Handbook of Qualitative Research.* 3rd ed.. edn. Thousand Oaks, CA ; London: Thousand Oaks, CA ; London : SAGE Publications
- DiCicco-Bloom, B. and Crabtree, B. F. (2006) 'The Qualitative Research Interview'. *Medical Education* 40 (4), 314-321

Dickson-Swift, V., James, E. L., Kippen, S., and Liamputtong, P. (2006) 'Blurring Boundaries in Qualitative Health Research on Sensitive Topics'. *Qualitative Health Research* 16 (6), 853-871

Dirks, T. and HADDERS-ALGRA, M. (2011) 'The Role of the Family in Intervention of Infants at High Risk of Cerebral Palsy: A Systematic Analysis'. *Developmental Medicine & Child Neurology* 53 (s4), 62-67

Dollahite, D. C. (2003) 'Fathering for Eternity: Generative Spirituality in Latter-Day Saint Fathers of Children with Special Needs'. *Review of Religious Research*, 44 (3), 237-251

Donald, K. A., Kakooza, A. M., Wammanda, R. D., Mallewa, M., Samia, P., Babakir, H., Bearden, D., Majnemer, A., Fehlings, D., Shevell, M., Chugani, H., and Wilmshurst, J. M. (2015) 'Pediatric Cerebral Palsy in Africa: Where are we?'. *Journal of Child Neurology* 30 (8), 963-971

Dowling, M. (2006) 'Approaches to Reflexivity in Qualitative Research'. *Nurse Researcher* 13 (3), 7-21

Dowling, M. (2007) 'From Husserl to Van Manen. A Review of Different Phenomenological Approaches'. *International Journal of Nursing Studies* 44 (1), 131-142

Doyle, S. (2007) 'Member Checking with Older Women: A Framework for Negotiating Meaning'. *Health Care for Women International* 28 (10), 888-908

Drew, N. (2004) 'Creating a Synthesis of Intentionality: The Role of the Bracketing Facilitator'. *Advances in Nursing Science* 27 (3), 215-223

Eker, L. and Tüzün, E. H. (2004) 'An Evaluation of Quality of Life of Mothers of Children with Cerebral Palsy'. *Disability and Rehabilitation* 26 (23), 1354-1359

Elhassani, S. B. (1982) 'The Many Faces of Methylmercury Poisoning'. *Journal of Toxicology.Clinical Toxicology* 19 (8), 875-906

El-Tallawy, H. N., Farghaly, W., Shehata, G. A., Metwally, N. A., Rageh, T. A., and Abo-Elfetoh, N. (2011) 'Epidemiology of Cerebral Palsy in El-Kharga District-New Valley (Egypt)'. *Brain and Development* 33 (5), 406-411

Englander, M. (2012) 'The Interview: Data Collection in Descriptive Phenomenological Human Scientific Research\*'. *Journal of Phenomenological Psychology* 43 (1), 13-35

Enweronu-Laryea, C., Nkyekyer, K., and Rodrigues, O. (2008) 'The Impact of Improved Neonatal Intensive Care Facilities on Referral Pattern and Outcome at a Teaching Hospital in Ghana'. *Journal of Perinatology* 28 (8), 561-565

Etherington, K. (2004) 'Research Methods: Reflexivities-Roots, Meanings, Dilemmas'. *Counselling and Psychotherapy Research* 4 (2), 46-47

Faigenbaum, A. D., Kraemer, W. J., Blimkie, C. J., Jeffreys, I., Micheli, L. J., Nitka, M., and Rowland, T. W. (2009) 'Youth Resistance Training: Updated Position Statement Paper from the National Strength and Conditioning Association'. *Journal of Strength and Conditioning Research / National Strength & Conditioning Association* 23 (5 Suppl), S60-79

Farnes, C., Beckstrand, R., and Callister, L. (2011) 'Help-seeking Behaviours in Childbearing Women in Ghana, West Africa'. *International Nursing Review* 58 (4), 491-497

Ferragina, E. and Seeleib-Kaiser, M. (2011) 'Thematic Review: Welfare Regime Debate: Past, Present, Futures?'. *Policy & Politics* 39 (4), 583-611

Finlay, L. (2002) 'Negotiating the Swamp: The Opportunity and Challenge of Reflexivity in Research Practice'. *Qualitative Research* 2 (2), 209-230

Finlay, L. (2002b) "'Outing" the Researcher: The Provenance, Process, and Practice of Reflexivity'. *Qualitative Health Research* 12 (4), 531-545

Finlay, L. (2009) 'Debating Phenomenological Research Methods'. *Phenomenology & Practice* 3 (1)

Gajdosik, C. G. and Cicirello, N. (2002) 'Secondary Conditions of the Musculoskeletal System in Adolescents and Adults with Cerebral Palsy'. *Physical & Occupational Therapy in Pediatrics* 21 (4), 49-68

Gearing, R. E. (2004) 'Bracketing in Research: A Typology'. *Qualitative Health Research* 14 (10), 1429-1452

Geere, J., Gona, J., Omondi, F., Kifalu, M., Newton, C., and Hartley, S. (2013) 'Caring for Children with Physical Disability in Kenya: Potential Links between Caregiving and Carers' Physical Health'. *Child: Care, Health and Development* 39 (3), 381-392

Gergen, K. J. (1985) 'The Social Constructionist Movement in Modern Psychology.'. *American Psychologist* 40 (3), 266

Ghana Statistical Service (2008) Ghana Living Standards Survey Report Of The Fifth Round . Available online

Gibbs, A. (1997) 'Focus Groups'. *Social Research Update* 19 (8), 1-8

Gibbs, G. R. (2008) *Analysing Qualitative Data.*: Sage



- Gibson, B. E. and Martin, D. K. (2003) 'Qualitative Research and Evidence-Based Physiotherapy Practice'. *Physiotherapy* 89 (6), 350-358
- Giddens, A. (1977) 'New Rules of Sociological Method: A Positive Critique of Interpretative Sociologies'
- Gilbert, K. R. (2001) 'Introduction: Why are we Interested in Emotions'. *The Emotional Nature of Qualitative Research*, 3-15
- Gilligan, C. (1982) *In a Different Voice.*: Harvard University Press
- Gina, M. (2012) 'Understanding the Differences between Husserl's (Descriptive) and Heidegger's (Interpretive) Phenomenological Research'. *Journal of Nursing & Care*
- Giorgi, A. (1985) 'Sketch of a Psychological Phenomenological Method'. *Phenomenology and Psychological Research* 1, 23-85
- Giorgi, A. (1997) 'The Theory, Practice, and Evaluation of the Phenomenological Method as a Qualitative Research Procedure'. *Journal of Phenomenological Psychology* 28 (2), 235-260
- Giorgi, A. (2009) *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach.*: Duquesne University Press
- Giorgi, A. P. and Giorgi, B. M. (2003) 'The Descriptive Phenomenological Psychological Method.' In Camic, Paul M. (Ed); Rhodes, Jean E. (Ed); Yardley, Lucy (Ed), (2003). *Qualitative research in psychology: Expanding perspectives in methodology and design.* , (pp. 243-273). Washington, DC, US:
- Glenn, E. N. (2000) 'Creating a Caring Society'. *Contemporary Sociology* 29 (1), 84-94
- Gona, J. K., Xiong, T., Muhit, M. A., Newton, C. R., and Hartley, S. (2010) 'Identification of People with Disabilities using Participatory Rural Appraisal and Key Informants: A Pragmatic Approach with Action Potential Promoting Validity and Low Cost'. *Disability & Rehabilitation* 32 (1), 79-85
- Goodhead, A. and McDonald, J. (2007) 'Informal Caregivers Literature Review'. *A Report Prepared for the National Health Committee. Wellington: Health Services Centre, Victoria University of Wellington*
- Goodman, N. (1978) *Ways of Worldmaking.*: Hackett Publishing
- Grant, M. J. and Booth, A. (2009) 'A Typology of Reviews: An Analysis of 14 Review Types and Associated Methodologies'. *Health Information & Libraries Journal* 26 (2), 91-108

- Green, S. E. (2007) "'We're Tired, Not Sad': Benefits and Burdens of Mothering a Child with a Disability'. *Social Science & Medicine* 64 (1), 150-163
- Groce, N. (1999) 'Framing Disability Issues in Local Concepts and Beliefs.'. *Asia Pacific Disability Rehabilitation Journal* 10 (1), 4-7
- Guba, E. G. (1990) *The Paradigm Dialog.*: Sage Publications
- Guba, E. G. (1990) *The Paradigm Dialog.*: Sage Publications
- Guba, E. G. and Lincoln, Y. S. (1981) *Jossey-Bass Effective Evaluation: Improving the Usefulness of Evaluation Results through Responsive and Naturalistic Approaches.*: San Francisco, CA, US
- Guba, E. G. and Lincoln, Y. S. (1994) 'Competing Paradigms in Qualitative Research'. *Handbook of Qualitative Research* 2, 163-194
- Guest, G., Bunce, A., and Johnson, L. (2006) 'How many interviews are enough? An Experiment with Data Saturation and Variability'. *Field Methods* 18 (1), 59-82
- Haahr, A., Norlyk, A., and Hall, E. O. C. (2014) 'Ethical Challenges Embedded in Qualitative Research Interviews with Close Relatives'. *Nursing Ethics* 21 (1), 6-15
- Haley, J. and Harrigan, R. C. (2004) 'Voicing the Strengths of Pacific Island Parent Caregivers of Children Who are Medically Fragile'. *Journal of Transcultural Nursing* 15 (3), 184-194
- Haley, J. and Harrigan, R. C. (2004) 'Voicing the Strengths of Pacific Island Parent Caregivers of Children Who are Medically Fragile'. *Journal of Transcultural Nursing* 15 (3), 184-194
- Haley, J. M. (2009) 'A Transcultural Strengths Assessment Interview Guide for Parent Caregivers'. *Home Health Care Management & Practice* 21 (2), 90-98
- Haley, J. M. (2009) 'A Transcultural Strengths Assessment Interview Guide for Parent Caregivers'. *Home Health Care Management & Practice* 21 (2), 90-98
- Hamill, C. and Sinclair, H. A. H. (2010) 'Bracketing - Practical Considerations in Husserlian Phenomenological Research'. *Nurse Researcher* 17 (2), 16-24
- Hammal, D., Jarvis, S. N., and Colver, A. F. (2004) 'Participation of Children with Cerebral Palsy is Influenced by Where they Live'. *Developmental Medicine & Child Neurology* 46 (5), 292-298
- Hammell, K. (2006) *Perspectives on disability and rehabilitation: Contesting assumptions, challenging practice* Edinburgh, Churchill Livingstone/Elsevier

Hammell, K. W. and Carpenter, C. (2004) *Qualitative Research in Evidence-Based Rehabilitation*.: Churchill Livingstone Edinburgh

Hammell, K. W., Carpenter, C., and Dyck, I. (2000) *Using Qualitative Research: A Practical Introduction for Occupational and Physical Therapists*.: Elsevier Health Sciences

Hamzat, T. K. and Mordi, E. L. (2007) 'Impact of Caring for Children with Cerebral Palsy on the General Health of their Caregivers in an African Community'. *International Journal of Rehabilitation Research.Internationale Zeitschrift Fur Rehabilitationsforschung.Revue Internationale De Recherches De Readaptation* 30 (3), 191-194

Hand, H. (2003) 'The Mentor's Tale: A Reflexive Account of Semi-Structured Interviews'. *Nurse Researcher* 10 (3), 15-27

Harbourne, R. T., Willett, S., Kyvelidou, A., Deffeyes, J., and Stergiou, N. (2010) 'A Comparison of Interventions for Children with Cerebral Palsy to Improve Sitting Postural Control: A Clinical Trial'. *Physical Therapy* 90 (12), 1881-1898

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., and Chavuta, A. (2005) 'How do Carers of Disabled Children Cope? the Ugandan Perspective'. *Child: Care, Health and Development* 31 (2), 167-180

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., and Chavuta, A. (2005) 'How do Carers of Disabled Children Cope? the Ugandan Perspective'. *Child: Care, Health and Development* 31 (2), 167-180

Helman, C.G., 2007. *Culture, health and illness*. 5<sup>th</sup> Edition CRC Press London.

Hertz, R. (1997) *Reflexivity & Voice*.: Sage Thousand Oaks, CA

Hirsh, A. T., Gallegos, J. C., Gertz, K. J., Engel, J. M., and Jensen, M. P. (2010) 'Symptom Burden in Individuals with Cerebral Palsy'. *Journal of Rehabilitation Research and Development* 47 (9), 863

Horsburgh, D. (2003) 'Evaluation of Qualitative Research'. *Journal of Clinical Nursing* 12 (2), 307-312

Horton, J., Macve, R., and Struyven, G. (2004) 'Qualitative Research: Experiences in using Semi-Structured Interviews'. *The Real Life Guide to Accounting Research*, 339-357

Houghton, C., Casey, D., Shaw, D., and Murphy, K. (2013) 'Rigour in Qualitative Case-Study Research'. *Nurse Researcher* 20 (4), 12-17

[http://laws.ghanalegal.com/acts/id/167/section/10/Functions\\_Of\\_District\\_Assemblies](http://laws.ghanalegal.com/acts/id/167/section/10/Functions_Of_District_Assemblies)

[http://www.statsghana.gov.gh/docfiles/glss5\\_report.pdf](http://www.statsghana.gov.gh/docfiles/glss5_report.pdf) accessed on July 31 2016

- Huang, Y. P., Kellett, U., and St John, W. (2011) 'Being Concerned: Caregiving for Taiwanese Mothers of a Child with Cerebral Palsy'. *Journal of Clinical Nursing* 21 (1-2), 189-197
- Huang, Y., Kellett, U. M., and St John, W. (2010) 'Cerebral Palsy: Experiences of Mothers After Learning their child's Diagnosis'. *Journal of Advanced Nursing* 66 (6), 1213-1221
- Hughes, J. A., Sharrock, W., and Martin, P. J. (2003) *Understanding Classical Sociology: Marx, Weber, Durkheim.*: Sage
- Hutton, J. and Pharoah, P. (2006) 'Life Expectancy in Severe Cerebral Palsy'. *Archives of Disease in Childhood* 91 (3), 254-258
- Hutton, J., Colver, A., and Mackie, P. (2000) 'Effect of Severity of Disability on Survival in North East England Cerebral Palsy Cohort'. *Archives of Disease in Childhood* 83 (6), 468-474
- Idro, R., Newton, C., Kiguli, S., and Kakooza-Mwesige, A. (2010) 'Child Neurology Practice and Neurological Disorders in East Africa'. *Journal of Child Neurology* 25 (4), 518-524
- Igo, S. (2014) . *The Essential Structure of Practising Evidence Based Practice: A Phenomenological Description of the Experiences of Physiotherapists*
- Im, E. and Chee, W. (2003) 'Feminist Issues in e-Mail Group Discussion among Cancer Patients'. *Advances in Nursing Science* 26 (4), 287-298
- Jadad, A. R., Moore, R. A., Carroll, D., Jenkinson, C., Reynolds, D. J. M., Gavaghan, D. J., and McQuay, H. J. (1996) 'Assessing the Quality of Reports of Randomized Clinical Trials: Is Blinding Necessary?'. *Controlled Clinical Trials* 17 (1), 1-12
- Jahnsen, R., Villien, L., Aamodt, G., Stanghelle, J., and Holm, I. (2004) 'Musculoskeletal Pain in Adults with Cerebral Palsy Compared with the General Population'. *Journal of Rehabilitation Medicine* 36 (2), 78-84
- James, A. (2001) 'Ethnography in the Study of Children and Childhood'. *Handbook of Ethnography*, 246-257
- Jeanfreau, S. G. and Jack, L., Jr (2010) 'Appraising Qualitative Research in Health Education: Guidelines for Public Health Educators'. *Health Promotion Practice* 11 (5), 612-617
- Jensen, G. M., Gwyer, J., and Shepard, K. F. (2000) 'Expert Practice in Physical Therapy'. *Physical Therapy* 80 (1), 28-43; discussion 44-52

- Jette, A. M. (2006) 'Toward a Common Language for Function, Disability, and Health'. *Physical Therapy* 86 (5), 726-734
- Johnson, R. B. (1997) 'Examining the Validity Structure of Qualitative Research'. *Education* 118 (2), 282
- Kafle, N. P. (2013) 'Hermeneutic Phenomenological Research Method Simplified'. *Bodhi: An Interdisciplinary Journal* 5 (1), 181-200
- Ketelaar, M., Vermeer, A., Hart, H., van Petegem-van Beek, E., and Helders, P. J. (2001) 'Effects of a Functional Therapy Program on Motor Abilities of Children with Cerebral Palsy'. *Physical Therapy* 81 (9), 1534-1545
- King, M., Speck, P., and Thomas, A. (1999) 'The Effect of Spiritual Beliefs on Outcome from Illness'. *Social Science & Medicine* 48 (9), 1291-1299
- King, S., Teplicky, R., King, G., and Rosenbaum, P. (eds.) (2004) *Seminars in Pediatric Neurology. 'Family-Centered Service for Children with Cerebral Palsy and their Families: A Review of the Literature'*: Elsevier
- Kittay, E. F. (1999). Not my way, Sessa, your way slowly. In Hanigsberg, Julia E and Ruddick, S. (1999) *Mother Troubles: Rethinking Contemporary Maternal Dilemmas* (pp. 3-27): Boston, MA: Beacon Press
- Klinger, L. (2005) 'Occupational Adaptation: Perspectives of People with Traumatic Brain Injury'. *Journal of Occupational Science* 12 (1), 9-16
- Koch, T. and Harrington, A. (1998) 'Reconceptualizing Rigour: The Case for Reflexivity'. *Journal of Advanced Nursing* 28 (4), 882-890
- Koch, T. and Harrington, A. (1998) 'Reconceptualizing Rigour: The Case for Reflexivity'. *Journal of Advanced Nursing* 28 (4), 882-890
- Krauss, S. E. (2005) 'Research Paradigms and Meaning Making: A Primer'. *The Qualitative Report* 10 (4), 758-770
- Krieger, S. (1991) *Social Science and the Self: Personal Essays on an Art Form.*: Susan Krieger
- Krigger, K. W. (2006) 'Cerebral Palsy: An Overview'. *American Family Physician* 73 (1), 91-100
- Kroeger, A. (1983) 'Anthropological and Socio-Medical Health Care Research in Developing Countries'. *Social Science & Medicine* 17 (3), 147-161

- Kumar, S. G., Roy, G., and Kar, S. S. (2012) 'Disability and Rehabilitation Services in India: Issues and Challenges'. *Journal of Family Medicine and Primary Care* 1 (1), 69-73
- Kuo, Y. and Lach, L., M. (2012) 'Life Decisions of Taiwanese Women Who Care for a Sibling with Cerebral Palsy'. *Health Care for Women International* 33 (7), 646-665
- Laird, S. E. (2011) 'Social Work with Children and Families in Ghana: Negotiating Tradition and Modernity'. *Child & Family Social Work* 16 (4), 434-443
- Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., Young, N., and Hanna, S. (2007) 'Patterns of Participation in Recreational and Leisure Activities among Children with Complex Physical Disabilities'. *Developmental Medicine & Child Neurology* 48 (5), 337-342
- Lawlor, K., Mihaylov, S., Welsh, B., Jarvis, S., and Colver, A. (2006) 'A Qualitative Study of the Physical, Social and Attitudinal Environments Influencing the Participation of Children with Cerebral Palsy in Northeast England'. *Pediatric Rehabilitation* 9 (3), 219-228
- Lazarus, R. S. (2006) 'Emotions and Interpersonal Relationships: Toward a person-centered Conceptualization of Emotions and Coping'. *Journal of Personality* 74 (1), 9-46
- LeVasseur, J. J. (2003) 'The Problem of Bracketing in Phenomenology'. *Qualitative Health Research* 13 (3), 408-420
- Levitt, S. and Pickering, D. (2010) *Treatment of Cerebral Palsy and Motor Delay*.: Wiley Online Library
- Levitt, S. and Pickering, D. (2010) *Treatment of Cerebral Palsy and Motor Delay*.: Wiley Online Library
- Lincoln, Y. S. and Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage
- LOCAL GOVERNMENT ACT - 1993 (ACT 462 Section - 10 - Functions of District Assemblies
- Lopez, K. A. and Willis, D. G. (2004) 'Descriptive Versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge'. *Qualitative Health Research* 14 (5), 726-735
- Mac Keith, R., Mackenzie, I., and Polani, P. (1959) 'Definition of Cerebral Palsy'. *Developmental Medicine & Child Neurology* 1 (5), 23-23
- Magill-Evans, J., Darrah, J., and Galambos, N. L. (2011) 'The Parenting Journey of Mothers of Young Adults with Multiple Impairments'. *Journal of Developmental and Physical Disabilities* 23 (3), 183-193

- Majnemer, A., Shevell, M., Rosenbaum, P., and Abrahamowicz, M. (2002) 'Early Rehabilitation Service Utilization Patterns in Young Children with Developmental Delays'. *Child: Care, Health and Development* 28 (1), 29-37
- Maloni, P. K., Despres, E. R., Habbous, J., Primmer, A. R., Slatten, J. B., Gibson, B. E., and Landry, M. D. (2010) 'Perceptions of Disability among Mothers of Children with Disability in Bangladesh: Implications for Rehabilitation Service Delivery'. *Disability and Rehabilitation* 32 (10), 845-854
- Manias, E. and Street, A. (2001) 'Rethinking Ethnography: Reconstructing Nursing Relationships'. *Journal of Advanced Nursing* 33 (2), 234-242
- Marshall, M. N. (1996) 'Sampling for Qualitative Research'. *Family Practice* 13 (6), 522-525
- Martin, L., Baker, R., and Harvey, A. (2010) 'A Systematic Review of Common Physiotherapy Interventions in School-Aged Children with Cerebral Palsy'. *Physical & Occupational Therapy in Pediatrics* 30 (4), 294-312
- Mason, M. (ed.) (2010) 'Sample Size and Saturation in PhD Studies using Qualitative Interviews' *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*. (Vol. 11, No. 3).
- Masri, A., Hamamy, H., and Khreisat, A. (2011) 'Profile of Developmental Delay in Children Under Five Years of Age in a Highly Consanguineous Community: A Hospital-Based study–Jordan'. *Brain and Development* 33 (10), 810-815
- Masterson, M., K. (2010) *Chronic Sorrow in Mothers of Adult Children with Cerebral Palsy: An Exploratory Study*. [online] thesis or dissertation: Kansas State University
- Maulik, P. K. and Darmstadt, G. L. (2007) 'Childhood Disability in Low-and Middle-Income Countries: Overview of Screening, Prevention, Services, Legislation, and Epidemiology'. *Pediatrics* 120 (Supplement 1), S1-S55
- Mazer, B., Feldman, D., Majnemer, A., Gosselin, J., and Kehayia, E. (2006) 'Rehabilitation Services for Children: Therapists' Perceptions'. *Developmental Neurorehabilitation* 9 (4), 340-350
- McDonnell, A., Jones, M. L., and Read, S. (2000) 'Practical Considerations in Case Study Research: The Relationship between Methodology and Process'. *Journal of Advanced Nursing* 32 (2), 383-390
- McIlfatrick, S., Sullivan, K., and McKenna, H. (2006) 'Exploring the Ethical Issues of the Research Interview in the Cancer Context'. *European Journal of Oncology Nursing* 10 (1), 39-47

- McNally, A. and Mannan, H. (2013) 'Perceptions of Caring for Children with Disabilities: Experiences from Moshi, Tanzania'. *African Journal of Disability* 2 (1), 1-10
- Milbrath, V. M., Cecagno, D., Soares, D. C., Amestoy, S. C., and Siqueira, Hedi Crecencia Heckler de (2008) 'Being a Woman, Mother to a Child with Cerebral Palsy'. *Acta Paulista De Enfermagem* 21 (3), 427-431
- Miller, S. (2003) 'Analysis of Phenomenological Data Generated with Children as Research Participants'. *Nurse Researcher* 10 (4), 68-82
- Mills, S., Williams, J. E., Adjuk, M., and Hodgson, A. (2008) 'Use of Health Professionals for Delivery Following the Availability of Free Obstetric Care in Northern Ghana'. *Maternal and Child Health Journal* 12 (4), 509-518
- Moore, L. A. (2005) . *The Lived Experience of being a Mother of a Child with Severe Cerebral Palsy* {online} Master of Science Thesis. Medical College of Ohio. <http://utdr.utoledo.edu/cgi/viewcontent.cgi?article=2473&context=theses-dissertations>
- Moran, D. (2005) 'Husserl: Founder of Phenomenology'. Polity, Cambridge
- Moran, D. and Mooney, T. (2002) *The Phenomenology Reader.*: Psychology Press
- Morris, C. (2007) 'Definition and Classification of Cerebral Palsy: A Historical Perspective'. *Developmental Medicine & Child Neurology* 49 (s109), 3-7
- Morse, J. M. (1995) 'The Significance of Saturation'. *Qualitative Health Research* 5 (2), 147-149
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., and Spiers, J. (2008) 'Verification Strategies for Establishing Reliability and Validity in Qualitative Research'. *International Journal of Qualitative Methods* 1 (2), 13-22
- MOTSCH, H. (2008) 'The Participatory Development of International Guidelines for CBR'. *Lepr Rev* 79, 17-29
- Moustakas, C. (1994) *Phenomenological Research Methods.*: Sage Publications
- Moyer, C. A., Adongo, P. B., Aborigo, R. A., Hodgson, A., Engmann, C. M., and DeVries, R. (2014) "It's Up to the woman's People": How Social Factors Influence Facility-Based Delivery in Rural Northern Ghana'. *Maternal and Child Health Journal* 18 (1), 109-119
- Muecke, M (1994) 'On the evaluation of ethnography'. In Morse, J. M. *Critical Issues in Qualitative Research Methods.*: Sage
- Munhall, P. L. ( 2007). *Nursing Research: A qualitative perspective* ( 3<sup>rd</sup> ed) Sudbury: Jones & Bartlett



- Naami, A. (2014) 'Breaking the Barriers: Ghanaians' Perspectives about the Social Model'. *Disability, CBR & Inclusive Development* 25 (1), 21-39
- Nagle, S., Cook, J. V., and Polatajko, H. J. (2002) 'I'm Doing as Much as I can: Occupational Choices of Persons with a Severe and Persistent Mental Illness'. *Journal of Occupational Science* 9 (2), 72-81
- Nicholls, D. A. and Gibson, B. E. (2010) 'The Body and Physiotherapy'. *Physiotherapy Theory and Practice* 26 (8), 497-509
- Nikander, P. (2008) 'Working with Transcripts and Translated Data'. *Qualitative Research in Psychology* 5 (3), 225-231
- Nimbalkar, S., Raithatha, S., Shah, R., and Panchal, D. A. (2014) 'A Qualitative Study of Psychosocial Problems among Parents of Children with Cerebral Palsy Attending Two Tertiary Care Hospitals in Western India'. *ISRN Family Medicine* 2014
- Norlyk, A. and Harder, I. (2010) 'What Makes a Phenomenological Study Phenomenological? an Analysis of Peer-Reviewed Empirical Nursing Studies'. *Qualitative Health Research* 20 (3), 420-431
- Northway, R. (2000) 'Disability, Nursing Research and the Importance of Reflexivity'. *Journal of Advanced Nursing* 32 (2), 391-397
- Novak, I., Cusick, A., and Lannin, N. (2009) 'Occupational Therapy Home Programs for Cerebral Palsy: Double-Blind, Randomized, Controlled Trial'. *Pediatrics* 124 (4), e606-14
- Novak, I., Hines, M., Goldsmith, S., and Barclay, R. (2012) 'Clinical Prognostic Messages from a Systematic Review on Cerebral Palsy'. *Pediatrics* 130 (5), e1285-e1312
- Nyante, G. G., Baltussen, M.M., and Asante, S. (2012). Situational analysis of programmes on childhood disability in Dangbe West District in Ghana. Unpublished
- Nyonator, F. K., Awoonor-Williams, J. K., Phillips, J. F., Jones, T. C., and Miller, R. A. (2005) 'The Ghana Community-Based Health Planning and Services Initiative for Scaling Up Service Delivery Innovation'. *Health Policy and Planning* 20 (1), 25-34
- Obladen, M. (2011) 'Lame from Birth: Early Concepts of Cerebral Palsy'. *Journal of Child Neurology* 26 (2), 248-256
- O'Byrne, P. and Holmes, D. (2008) 'Researching Marginalized Populations: Ethical Concerns about Ethnography'. *CJNR (Canadian Journal of Nursing Research)* 40 (3), 144-159
- Odding, E., Roebroek, M. E., and Stam, H. J. (2006) 'The Epidemiology of Cerebral Palsy: Incidence, Impairments and Risk Factors'. *Disability & Rehabilitation* 28 (4), 183-

- Odman, P. and Oberg, B. (2005) 'Effectiveness of Intensive Training for Children with Cerebral Palsy-A Comparison between Child and Youth Rehabilitation and Conductive Education'. *Journal of Rehabilitation Medicine* 37 (4), 263
- Olawale, O. A., Deih, A. N., and Yaadar, R. K. (2013) 'Psychological Impact of Cerebral Palsy on Families: The African Perspective'. *Journal of Neurosciences in Rural Practice* 4 (2), 159-163
- Oliver, M. (1992) 'Changing the Social Relations of Research Production?'. *Disability, Handicap & Society* 7 (2), 101-114
- Oliver, M. (2009) 'The Social Model in Context'. *Rethinking Normalcy: A Disability Studies Reader*, 19-30
- Opheim, A., Jahnsen, R., Olsson, E., and Stanghelle, J. K. (2009) 'Walking Function, Pain, and Fatigue in Adults with Cerebral Palsy: A 7-year follow-up Study'. *Developmental Medicine & Child Neurology* 51 (5), 381-388
- Orb, A., Eisenhauer, L., and Wynaden, D. (2001) 'Ethics in Qualitative Research'. *Journal of Nursing Scholarship* 33 (1), 93-96
- Palisano, R. J., Chiarello, L. A., King, G. A., Novak, I., Stoner, T., and Fiss, A. (2012) 'Participation-Based Therapy for Children with Physical Disabilities'. *Disability and Rehabilitation* 34 (12), 1041-1052
- Parkes, J. and Hill, N. (2010) 'The Needs of Children and Young People with Cerebral Palsy.'. *Paediatric Nursing* 22 (4), 14
- Patton, M. (2002) 'Qualitative Research & Evaluation Methods' Thousand Oaks, CA.: SAGE Publications
- Patton, M. Q. (1990) *Qualitative Evaluation and Research Methods* Thousand Oaks, CA.: SAGE Publications
- Pearlin, L. I., Mullan, J. T., Semple, S. J., and Skaff, M. M. (1990) 'Caregiving and the Stress Process: An Overview of Concepts and their Measures'. *The Gerontologist* 30 (5), 583-594
- Pesonen, H., Remes, A. M., and Isola, A. (2011) 'Ethical Aspects of Researching Subjective Experiences in Early-Stage Dementia'. *Nursing Ethics* 18 (5), 651-61
- Pharoah, P., Cooke, T., Johnson, M., King, R., and Mutch, L. (1998) 'Epidemiology of Cerebral Palsy in England and Scotland, 1984-9'. *Archives of Disease in Childhood-Fetal and Neonatal Edition* 79 (1), F21-F25

- Pierce, D. (2009) 'Co-occupation: The Challenges of Defining Concepts Original to Occupational Science'. *Journal of Occupational Science* 16 (3), 203-207
- Poland, B. D. (1995) 'Transcription Quality as an Aspect of Rigor in Qualitative Research'. *Qualitative Inquiry* 1 (3), 290-310
- Pope, C. and Mays, N. (2008) *Qualitative Research in Health Care.*: John Wiley & Sons Publications.
- Priest, H. (2002) 'An Approach to the Phenomenological Analysis of Data.(Issues in Research)'. *Nurse Researcher* 10 (2), 50-64
- Primeau, L. A. (2003) 'Reflections on Self in Qualitative Research: Stories of Family'. *American Journal of Occupational Therapy* 57 (1), 9-16
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., and Wood, E. (2005) 'The Health and Well-being of Caregivers of Children with Cerebral Palsy'. *Pediatrics* 115 (6), e626-e636
- Randall, S. and Coast, E. (2015) 'Poverty in African Households: The Limits of Survey and Census Representations'. *The Journal of Development Studies* 51 (2), 162-177
- Rapp Jr, C. E. and Torres, M. M. (2000) 'The Adult with Cerebral Palsy'. *Archives of Family Medicine* 9 (5), 466
- Raskin, J. D. (2002) 'Constructivism in Psychology: Personal Construct Psychology, Radical Constructivism, and Social Constructionism'. *American Communication Journal* 5 (3), 1-25
- Raskin, J. D. (2011) 'On Essences in Constructivist Psychology.'. *Journal of Theoretical and Philosophical Psychology* 31 (4), 223
- Ratliffe, C. and Haley, J. (2002) 'Toward a Non-Dualistic Disability Paradigm: Beyond Connectedness'. *Disability Studies Quarterly* 22 (2)
- Ratliffe, C. and Haley, J. (2002) 'Toward a Non-Dualistic Disability Paradigm: Beyond Connectedness'. *Disability Studies Quarterly* 22 (2), 349-445
- Ratliffe, C. and Haley, J. (2002) 'Toward a Non-Dualistic Disability Paradigm: Beyond Connectedness'. *Disability Studies Quarterly* 22 (2)
- Ravallion, M. (1992) 'Poverty Comparisons—A Guide to Concepts and Methods:World Bank'. *Living Standards Measurement Study Working Paper* (88)
- Ray M (1994) The richness of phenomenology: philosophic, theoretic and methodologic concerns. In Morse JM (Ed) *Critical Issues in Qualitative Research Methods*. Thousand

Oaks, Sage.<http://www.paincommunitycentre.org/biblio/richness-phenomenology-philosophic-theoretic-and-methodologic-concerns>

Redmond, R. and Parrish, M. (2008) 'Variables Influencing Physiotherapy Adherence among Young Adults with Cerebral Palsy'. *Qualitative Health Research* 18 (11), 1501-1510

Reinharz, S. (1997) 'Who Am I? the Need for a Variety of Selves in the Field'. *Reflexivity and Voice*, 3-20

Relevance and applicability to physiotherapy' *Advances in Physiotherapy* 10: 110-118

Richardson, L. (1997) 'Skirting a Pleated Text: De-Disciplining an Academic Life'. *Qualitative Inquiry* 3 (3), 295-303

Ritchie, J., Lewis, J., Nicholls, C. M., and Ormston, R. (2013) *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Thousand Oaks, CA: Sage

Rodger, S. and Mandich, A. (2005) 'Getting the Run Around: Accessing Services for Children with Developmental co-ordination Disorder'. *Child: Care, Health and Development* 31 (4), 449-457

Rolls, L. and Relf, M. (2006) 'Bracketing Interviews: Addressing Methodological Challenges in Qualitative Interviewing in Bereavement and Palliative Care'. *Mortality* 11 (3), 286-305

Roos, S. (2002) *Chronic Sorrow: A Living Loss.*: Psychology Press, Brunner-Routledge, New York.

Rosenbaum, P. (2003) 'Cerebral Palsy: What Parents and Doctors Want to Know'. *BMJ: British Medical Journal* 326 (7396), 970

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., Dan, B., and Jacobsson, B. (2007) 'A Report: The Definition and Classification of Cerebral Palsy April 2006'. *Dev Med Child Neurol Suppl* 109 (8-14)

Roush, S. E. and Sharby, N. (2011) 'Disability Reconsidered: The Paradox of Physical Therapy'. *Physical Therapy* 91 (12), 1715-1727

Roush, S. E. and Sharby, N. (2011) 'Disability Reconsidered: The Paradox of Physical Therapy'. *Physical Therapy* 91 (12), 1715-1727

Rubinstein, Robert . (1994) "Proposal Writing." In *Qualitative Research Methods in Aging Research*, edited by J. Gubrium and A. Sankar. Thousand Oaks, CA: Sage.

- Russell, C. (2005) 'An Overview of the Integrative Research Review'. *Progress in Transplantation* 15 (1), 8-13
- Sackett, D. L. (1989) 'Rules of Evidence and Clinical Recommendations on the use of Antithrombotic Agents'. *CHEST Journal* 95 (2\_Supplement), 2S-4S
- Sam, D. L. (2001) 'Value of Children: Effects of Globalization on Fertility Behavior and Child-Rearing Practices in Ghana'. *Research Review* 17 (2), 5-16
- Sanders, C. (2003) 'Application of Colaizzi's Method: Interpretation of an Auditable Decision Trail by a Novice Researcher'. *Contemporary Nurse* 14 (3), 292-302
- Savage, S. and Bailey, S. (2004) 'The Impact of Caring on Caregivers' Mental Health: A Review of the Literature'. *Australian Health Review* 27 (1), 111
- Savin-Baden, M. and Major, C. H. (2013) *Qualitative Research: The Essential Guide to Theory and Practice*.: Routledge
- Scambler, G., 2004. Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory & Health*, 2(1), pp.29-46.
- Scheidegger, G., Lovelock, L., and Kinébanian, A. (2010) 'The Daily Lives and Occupations of Tibetan Families Who have a Child with Disabilities'. *Scandinavian Journal of Occupational Therapy* 17 (4), 286-298
- Schwandt, T. A. (1994) 'Constructivist, Interpretivist Approaches to Human Inquiry.' In Denzin, Norman K. (Ed); Lincoln, Yvonna S. (Ed), (1994). *Handbook of qualitative research*. , (pp. 118-137). Thousand Oaks, CA, US: Sage Publications, Inc, xii, 643 pp.
- Scianni, A., Butler, J. M., Ada, L., and Teixeira-Salmela, L. F. (2009) 'Muscle Strengthening is Not Effective in Children and Adolescents with Cerebral Palsy: A Systematic Review'. *Australian Journal of Physiotherapy* 55 (2), 81-87
- Seale, C. (1999) 'Quality in Qualitative Research'. *Qualitative Inquiry* 5 (4), 465-478
- Shakespeare, T. (2006) 'The Social Model of Disability'. *The Disability Studies Reader* 2, 197-204
- Shamir, M., Dickstein, R., and Tirosh, E. (2012) 'Intensive Intermittent Physical Therapy in Infants with Cerebral Palsy: A Randomized Controlled Pilot Study'. *The Israel Medical Association Journal: IMAJ* 14 (12), 737-741
- Sharma, M. (2005) 'Using Focus Groups in Community Based Rehabilitation'. *Asia Pacific Disability & Rehabilitation* 16, 41-50
- Shaw, J. A. and Connelly, D. M. (2012) 'Phenomenology and Physiotherapy: Meaning in Research and Practice'. *Physical Therapy Reviews* 17 (6), 398-408

- Shenton, A. K. (2004) 'Strategies for Ensuring Trustworthiness in Qualitative Research Projects'. *Education for Information* 22 (2), 63-75
- Shevell, M. I., Dagenais, L., and Hall, N. (2009) 'Comorbidities in Cerebral Palsy and their Relationship to Neurologic Subtype and GMFCS Level'. *Neurology* 72 (24), 2090-2096
- Shosha, G. A. (2012) 'Employment of Colaizzi's Strategy in Descriptive Phenomenology: A Reflection of a Researcher'. *European Scientific Journal* 8 (27)
- Smart, J. F. (2009) 'The Power of Models of Disability'. *Journal of Rehabilitation* 75 (2), 3
- Smith, J. K. and Deemer, D. K. (2000) 'The Problem of Criteria in the Age of Relativism'. *Handbook of Qualitative Research* 2, 877-896
- Smith, L. J. (2008) 'How Ethical is Ethical Research? Recruiting Marginalized, Vulnerable Groups into Health Services Research'. *Journal of Advanced Nursing* 62 (2), 248-257
- Soltis-Jarrett, V. (1997) 'The Facilitator in Participatory Action Research: Les Raisons d'Etre'. *Advances in Nursing Science* 20 (2), 45-54
- Speraw, S. (2006) 'Spiritual Experiences of Parents and Caregivers Who have Children with Disabilities Or Special Needs'. *Issues in Mental Health Nursing* 27 (2), 213-230
- Speziale, H. S., Streubert, H. J., and Carpenter, D. R. (2011) *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. Philadelphia: Lippincott Williams & Wilkins
- Squires, A. (2008) 'Language Barriers and Qualitative Nursing Research: Methodological Considerations'. *International Nursing Review* 55 (3), 265-273
- Steenbergen, B. and Gordon, A. M. (2006) 'Activity Limitation in Hemiplegic Cerebral Palsy: Evidence for Disorders in Motor Planning'. *Developmental Medicine & Child Neurology* 48 (09), 780-783
- Sullivan-Bolyai, S., Knafl, K. A., Sadler, L., and Gilliss, C. L. (2003) 'Great Expectations: A Position Description for Parents as Caregivers: Part I'. *Pediatric Nursing* 29 (6), 457
- Suri, H. (2011) 'Purposeful Sampling in Qualitative Research Synthesis'. *Qualitative Research Journal* 11 (2), 63-75
- Sykes, C. (2008) 'The International Classification of Functioning, Disability and Health: Therkleson, T. (2010) 'Ginger Compress Therapy for Adults with Osteoarthritis'. *Journal of Advanced Nursing* 66 (10), 2225-2233
- Thorne, S. (2000) 'Data Analysis in Qualitative Research'. *Evidence Based Nursing* 3 (3), 68-70

- Tinney, M., Chiodo, A., Haig, A., and Wiredu, E. (2007) 'Medical Rehabilitation in Ghana'. *Disability & Rehabilitation* 29 (11-12), 921-927
- Todres, L. (2005) 'Clarifying the Life-World: Descriptive Phenomenology'. *Qualitative Research in Health Care*, 104-124
- Touyama, M., Touyama, J., Ochiai, Y., Toyokawa, S., and Kobayashi, Y. (2013) 'Long-Term Survival of Children with Cerebral Palsy in Okinawa, Japan'. *Developmental Medicine & Child Neurology* 55 (5), 459-463
- Treloar, L. L. (2002) 'Disability, Spiritual Beliefs and the Church: The Experiences of Adults with Disabilities and Family Members'. *Journal of Advanced Nursing* 40 (5), 594-603
- Tsorlakis, N., Evaggelidou, C., Grouios, G., and Tsorbatzoudis, C. (2004) 'Effect of Intensive Neurodevelopmental Treatment in Gross Motor Function of Children with Cerebral Palsy'. *Developmental Medicine & Child Neurology* 46 (11), 740-745
- Tufford, L. and Newman, P. (2012) 'Bracketing in Qualitative Research'. *Qualitative Social Work* 11 (1), 80-96
- Turner, B. S. (2008) *The Body and Society: Explorations in Social Theory*.: SAGE
- Twinn, S. (1997) 'An Exploratory Study Examining the Influence of Translation on the Validity and Reliability of Qualitative Data in Nursing Research'. *Journal of Advanced Nursing* 26 (2), 418-423
- Uldall, P. (2012) 'Everyday Life and Social Consequences of Cerebral Palsy.'. *Handbook of Clinical Neurology* 111, 203-207
- Ulin, P. R., Robinson, E. T., and Tolley, E. E. (2012) *Qualitative Methods in Public Health: A Field Guide for Applied Research*. Hoboken, NJ: John Wiley & Sons
- UNICEF (2011) Ghana Child Protection: Creating a strong policy framework. Available on line: [http://www.unicef.org/ghana/protection\\_7532.html](http://www.unicef.org/ghana/protection_7532.html) accessed on 19th August 2016
- UNICEF (2013) Ghana: Advocating for development that leaves no child behind. Available on line [http://www.unicef.org/ghana/Ghana\\_Booklet\\_Final.pdf](http://www.unicef.org/ghana/Ghana_Booklet_Final.pdf) accessed on 19<sup>th</sup> August 2016.
- United Nations Human Rights (1990) Convention on the Rights of the Child. Available online: <http://www.ohchr.org> accessed on 20<sup>th</sup> August 2016
- Ustad, T., Sorsdahl, A. B., and Ljunggren, A. E. (2009) 'Effects of Intensive Physiotherapy in Infants Newly Diagnosed with Cerebral Palsy'. *Pediatric Physical Therapy* 21 (2), 140-148

- Van Kaam, A. (1966) 'Existential Foundations of Psychology.' New York Doubleday
- Van Manen, M. (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy.*: Suny Press
- Vernon A. (1997) Reflexivity: the dilemmas of researching from the inside. In *Doing Disability Research* (Barnes, C. & Mercer G., eds), The Disability Press, Leeds, pp. 158-176
- Verschuren, O., Ada, L., Maltais, D. B., Gorter, J. W., Scianni, A., and Ketelaar, M. (2011) 'Muscle Strengthening in Children and Adolescents with Spastic Cerebral Palsy: Considerations for Future Resistance Training Protocols'. *Physical Therapy* 91 (7), 1130-1139
- Webb, C. and Kevern, J. (2001) 'Focus Groups as a Research Method: A Critique of some Aspects of their use in Nursing Research'. *Journal of Advanced Nursing* 33 (6), 798-8
- Weindling, A. M., Cunningham, C., Glenn, S., Edwards, R., and Reeves, D. (2007) *Additional Therapy for Young Children with Spastic Cerebral Palsy: A Randomised Controlled Trial.*: Gray Publishing
- Werner, D. (1999). Disabled village children. Hesperian foundation. Online. Available at <http://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00208.html#part1chap6> (10th February 2014) 05
- Werner, D. (1999). Disabled village children. Hesperian foundation. Online. Available online <http://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00208.html#part1chap6> (10th February 2014)
- Westbom, L., Bergstrand, L., Wagner, P., and Nordmark, E. (2011) 'Survival at 19 Years of Age in a Total Population of Children and Young People with Cerebral Palsy'. *Developmental Medicine & Child Neurology* 53 (9), 808-814
- Whitehead, J. (2004) 'What Counts as Evidence in Self-Studies of Teacher Education Practices'. in *International Handbook of Self-Study of Teaching and Teacher Education Practices*. ed. by Anon: Springer, 871-903
- Whittingham, K., Wee, D., Sanders, M., and Boyd, R. (2011) 'Responding to the Challenges of Parenting a Child with Cerebral Palsy: A Focus Group'. *Disability & Rehabilitation* 33 (17), 1557-1567
- Wichers, M., Odding, E., Stam, H., and Van Nieuwenhuizen, O. (2005) 'Clinical Presentation, Associated Disorders and Aetiological Moments in Cerebral Palsy: A Dutch Population-Based Study'. *Disability & Rehabilitation* 27 (10), 583-589



Wollenhaupt, J. M. (2010) *The Experience of Mothers and Fathers with their Premature Infant in the Family Home.*: The University Of Wisconsin-Milwaukee

World Confederation of Physical Therapy (2015) Ghana Physiotherapy Association online available at <http://www.wcpt.org/node/24012> Accessed on 30<sup>th</sup> May 2016

World Health Organization (2001) 'International Classification of Functioning, Disability and Health. Geneva'. *World Health Organization*, 1-303

World Health Organization (2007) *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY.*: World Health Organization

World Health Organization (2007) *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY.*: World Health Organization

World Health Organization (2014) Country Cooperation Strategy at a glance [http://www.who.int/countryfocus/cooperation\\_strategy/ccsbrief\\_gha\\_en.pdf](http://www.who.int/countryfocus/cooperation_strategy/ccsbrief_gha_en.pdf) Accessed on 30<sup>th</sup> May 2016

World health report (2000) - Health systems: improving performance online available at <http://www.who.int/whr/2000/en/> Accessed on 30<sup>th</sup> May 2016

World Medical Association. (2001) 'World Medical Association Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects'. *Bulletin of the World Health Organization* 79 (4), 373-374

Wrigley-Asante, C. (2008) 'Men are Poor but Women are Poorer: Gendered Poverty and Survival Strategies in the Dangme West District of Ghana'. *Norsk Geografisk Tidsskrift-Norwegian Journal of Geography* 62 (3), 161-170

Wu, Y. W., Xing, G., Fuentes-Afflick, E., Danielson, B., Smith, L. H., and Gilbert, W. M. (2011) 'Racial, Ethnic, and Socioeconomic Disparities in the Prevalence of Cerebral Palsy'. *Pediatrics* 127 (3), e674-e681

Yabunaka, Y., Kondo, I., Sonoda, S., Saitoh, E., Tsuruta, Y., Konaka, M., Konaka, T., and Kawarada, S. (2011) 'Evaluating the Effect of Intensive Intervention Children with Cerebral Palsy using a Hypothetical Matched Control Group: A Preliminary Study'. *American Journal of Physical Medicine and Rehabilitation*

Yeargin-Allsopp, M., Braun, K. V. N., Doernberg, N. S., Benedict, R. E., Kirby, R. S., and Durkin, M. S. (2008) 'Prevalence of Cerebral Palsy in 8-Year-Old Children in Three Areas of the United States in 2002: A Multisite Collaboration'. *Pediatrics* 121 (3), 547-554

Yeboah, T. (2000) 'Improving the Provision of Traditional Health Knowledge for Rural Communities in Ghana\*'. *Health Libraries Review* 17 (4), 203-208

Yin, R. K. (2003) *Case Study Research: Design and Methods*. Thousand Oaks, CA: Sage

Zarb, G. (1992) 'On the Road to Damascus: First Steps Towards Changing the Relations of Disability Research Production'. *Disability, Handicap & Society* 7 (2), 125-138.

Ziviani, J., Darlington, Y., Feeney, R., Rodger, S., and Watter, P. (2014) 'Early Intervention Services of Children with Physical Disabilities: Complexity of Child and Family Needs'. *Australian Occupational Therapy Journal* 61 (2), 67-75

## Appendix 1 Invitation Flyer

### APPENDIX 1: INVITATION FLYER



COVENTRY UNIVERSITY

UNIVERSITY OF GHANA

# Volunteers Needed for Research Study

#### TITLE OF STUDY

An Exploration of the Experiences and Perceptions of Primary Caregivers of Children with Cerebral Palsy Living in Rural Communities in Ghana

#### DESCRIPTION OF STUDY

I am doing a research study about the experiences of people who are caring for children with cerebral palsy. Your participation will involve an interview in English, Twi or Ga

If you provide care for a child with cerebral palsy, I would be grateful if you would share your experience with me

#### TO LEARN MORE, CONTACT

**Gifty Gyamah Nyante**  
Principal Investigator of the Study  
Mob: 0243302262 or [ggnyante@chs.edu.gh](mailto:ggnyante@chs.edu.gh)



This research is conducted through Coventry University and has been reviewed and approved by the Ghana Health Service Research Ethics Committee.

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*Together we can bring sunshine into the lives of children with cerebral palsy*

## **Appendix II Caregivers Information Sheet**

Title of project: An exploration of the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana

You are being invited to take part in this research study because you have experience of caring for a child with cerebral palsy. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Part 1 tells you about the purpose of this study and what will be required of you if you take part.

Part 2 gives you more detailed information about how the study will be conducted.

We encourage you to ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **Part 1**

This study is being conducted as part of a Doctoral program I am doing at Coventry University in the United Kingdom. The purpose of this study is to better understand the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana. It is hoped that this information will assist in identifying the positive and negative stressors of caregivers of children with cerebral palsy and what services would help support the care of children with cerebral palsy.

You are invited to take part in this study because you are caring for a child with cerebral palsy. Other caregivers will also be invited. If you agree to take part in this study, you will be asked questions about your experiences of taking care of a child with cerebral palsy including how you came to become the caregiver, how it impacts your life, and what helps and hinders your ability to care for the child and what support you received to date. You will be asked to participate in an informal face-to-face interview lasting between 60 and 90 minutes. The conversation will be recorded on a tape recorder so that the researcher can review and analyse what is said during the interview. This interview will take place in a location of your choice. All the information you give us in the interview will be kept confidential, only the researcher (Gifty Nyante) and her Director of Studies will have access to this information.

Should you have any concerns about the study, being invited to participate in this study or any problem you experienced as a result of the study please contact the researcher Gifty Nyante by telephone 0244251638 or 0243302262, or by e-mail: [ggnyante@chs.edu.gh](mailto:ggnyante@chs.edu.gh). Failing this you may wish to contact the Coventry University Ethics Committee chair, Professor Ian Marshall, in writing at AB,122, Coventry University, Priory street, Coventry CV1 5FB or by telephone on +44 24 7688 5293

*This completes Part 1 of the Information Sheet.*

*If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.*

## Part 2

Please note that all information provided would be anonymous, that is, at no time in the research process or when the results are reported will you be personally identified. Some of your statements will be quoted verbatim in reporting the study results to highlight the experience being described. The information obtained in the interview will only be used for the purposes of this study. You are free to withdraw from this study at anytime after signing or thumb printing the consent form without giving a reason. During the interview you will be free to choose not to answer any of the questions or request that the tape recorder to be turned off. Taking part in this study will not cause you any expense neither will you be paid to participate. We do not anticipate that being involved in this study will cause you any harm nor will there be any obvious benefits. We hope that, as a result of this study, we may be able to recommend ways of supporting people, like yourself, who care for children with cerebral palsy.

Thank you for considering being involved with this study.




## Appendix III Consent Form

**SCHOOL OF BIOMEDICAL AND ALLIED HEALTH  
SCIENCES**  
**COLLEGE OF HEALTH SCIENCES**  
**UNIVERSITY OF GHANA**  
**DEPARTMENT OF PHYSIOTHERAPY**

Phone: +233-0302-632276  
E-mail: physio.sahs@chs.edu.gh

My Ref. No. SAHS  
Your Ref. No.



P O Box KB 143  
Korle Bu  
Accra  
Ghana

**CONSENT FORM**

**Title of Study:** An exploration of the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana

Name of Researcher:

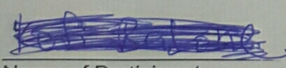
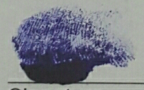
Please initial box

☒ I confirm that I have read and understand the information sheet dated .....  
(version .....) for the above study. I have had the opportunity to consider the  
information, ask questions and have had these answered satisfactorily.

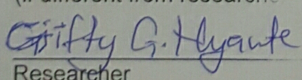
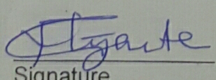
☒ I understand that my participation is voluntary and that I am free to withdraw at any time,  
without giving any reason, without my medical care or legal rights being affected.

☒ I understand that the Community Health Nurse will be informed of my participation in the  
study.

☒ I agree to take part in the above study.

            15 October 2014  
Name of Participant      Signature      Date

Name of Person taking consent (if different from researcher)      Signature      Date

            15/10/2014  
Researcher      Signature      Date

When completed a copy will be given to the participant and the original will be kept by the researcher

## **Appendix IV Guide of Broad Interview Questions**

### **Initial information**

1. What culture or ethnic group do you belong?
2. How old are you and how old is (child's name)?
3. What is your relationship with (child's name)?
4. How long have you been taking care of (child's name)?
5. How would you explain the problems you think (child's name) has?
6. How do you name the condition you think (child's name) has?
7. How did you get to know about (child's name) condition?
8. How would you describe the condition to someone who doesn't know (child's name)?
9. What do you think (child's name) future will be like?
10. What do you think a caregiver of a child with cerebral palsy needs in order to be able to care for them as well as possible?
11. What other children are caring for?
12. How do you feel about your care giving responsibilities?

### **Interview guide developed from literature**

#### **A. Strength recognized sources questions**

1. Positive attitude: How does your personality help you care for the child?
2. Spirituality: How important are your spiritual beliefs in helping you care for the child? How do they help you?
3. Family/Community Support: What support do you get from your family members and the community members that assists you in caring for (child's name)?
4. Taking Care of Self: How do you take care of yourself?
5. Finding Meanings: What do you think having cerebral palsy and a disability means?
6. Resourcefulness: What have you found useful to you in taking care of (child's name)?

#### **B. Negative sources**

1. Pre-existing Stressors: Can you describe any stressful events you have experienced since you started caring for (child's name)?
2. Financial: How do you manage financially since you started caring for (child's name)?
3. Role conflict: How has caring for (child's name) affected your other roles and responsibilities?
4. Isolation: How has caring for (child's name) affected your social participation?
5. Is there anything else you would like to tell me about what it is like to care for (child's name)? Thank you



## **Appendix V Reflections on Research Journey**

### **Pre research stage**

I conceived the idea of doing this research as a result of a situational analysis that revealed that there exist many children with cerebral palsy in community who are not receiving any form of rehabilitation. The only health professionals attending to these children were Community Health Nurses. I gained access through a network with the community health nurses and a special educationist in the community. Working with the special educationist was sometimes accompanied with feelings of uneasiness because I did not want to tell him what to say. One reason was because he was a man and also older than me (in the Ghanaian society women are expected to respect men and the elderly). Upon meeting the Special teacher, I emphasised the fact that I was a research student combining my research towards my PhD and working as a lecturer at the University. I felt that if I was perceived as a partner to the NGO, or an expert, the people would see me as someone who was going to provide solutions to their problems either financially or medically and might exaggerate their experiences. I monitored this by doing a comprehensive introduction of myself to the caregiver to counteract any adverse introduction made by the special teacher. I then arranged with the special teacher to see the caregivers of the children identified.

The experiences I gained from the pilot study prepared me well for the main interviews. In order to allow my readers to appreciate the difficulties I encountered during the data collection process, I decided to include a section in the main thesis that described the details of the participant recruitment (3.4.2.1. pages 97 to 101) .

How many interviews will be enough!!! This question motivated me to read more on the number of interviews needed for a phenomenological study. The literature affirms the number of participants for the research. As novice qualitative researcher, the transcription, and analysis was a dreadful task. For several months I couldn't sleep well, always panicking that I might not be able to complete the thesis. Thanks to my expert and experienced supervisory team that guided me through the process.

## **Appendix VI Contribution to the Nursing and Midwifery Training Programmes**

### **Curricula**

**Cover Page : Curriculum for the Registered Community Health Nursing**

**List of Technical Expert Page**

**General course outline Presented to Tutors**



Curriculum for the  
**Registered  
Community Nursing**  
(RCN) Programme

Based on the Semester Course Unit System

OCTOBER 2015







## REGISTERED MIDWIFERY CURRICULUM

To the immediate past Registrar/Chief Executive Officer, Rev. Veronica Darko, the Council acknowledges the visionary role she played in kick starting this curriculum review.

The Council also extends its deep sense of appreciation to the Registrar, Felix Nyante (FWACN, FGCNM) for the excellent leadership role he played in completing this curriculum review.

The Council further recognizes the technical expertise of the following persons during the review:

1. Felix Nyante	- Registrar
2. Veronica Darko	- Immediate Past Registrar
3. Dr. Magda Robalo	- Country Representative, WHO Ghana
4. Dr. Mrs. Roseline Dansowaa Doe	- MCH Officer, WHO Ghana
5. Dr. Nana Ama Brantuo	- WHO Ghana
6. Chantelle Allen	- Country Director, Jhpiego Ghana
7. Martha Serwah Appiagyei	- Snr. Technical Advisor, Jhpiego Ghana
8. Joyce Ablordeppey	- Snr. Technical Advisor, Jhpiego Ghana
9. Etta Forson Addo	- Technical Advisor, Jhpiego Ghana
10. Dora L. Kaki Agbodza	- Technical Advisor, Jhpiego Ghana
11. Rita Nyeduala	- Prog. Coordinator, Jhpiego Ghana
12. Tony Kwame Apadzi	- NAS – MOH
13. Alice Nkori	- FHI360/FANTA II Ghana
14. Viktor Playe	- USAID DELIVER PROJECT
15. Daniel Owusu-Afranie	- USAID DELIVER PROJECT
16. Mujasi Paschal	- USAID DELIVER PROJECT
17. Roya Sadri-Zadeh	- UNFPA
18. Anthony Dogbedo	- UNFPA
19. Adjoa Yenyi	- UNFPA
20. Frederica Hanson	- Formerly of UNFPA
21. Mary Gyasi	- National Population Council
22. Placide Tapsoba	- Country Director, Population Council
23. Selina F. Esantsi	- Snr. Prog. Officer, Population Council
24. Dela Kusi Appouh	- Staff Associate, Population Council
25. Marjolein Meande-Baltussen	- Country Coordinator, Ghana, CBM
26. Gifty G. Nyante	- Lecturer, UG/CBM
27. Patricia Kodjoe	- IPAS – Ghana
28. Selorme Kofi Azumah	- IPAS – Ghana
29. Dr. Yaa Asante	- GHS, Family Health Directorate
30. Dr. Isabella Sagoe-Moses	- GHS, Family Health Directorate
31. Rejoice Nutakor	- GHS, Family Health Directorate
32. Gifty Francisca Ben-Aryee	- GHS, Family Health Directorate
33. Angela Naa Odoi	- GHS, Family Health Directorate
34. Gifty M. Donkoh	- GHS, Family Health Directorate
35. Kate Quarshie	- GHS, Family Health Directorate
36. Elizabeth Adjei-Acquah	- GHS, Office of Chief Pharmacist
37. Winifred N.O. Armah-Attoh	- GHS, NACP
38. Charles Acquah	- GHS, PPME

## Course outline

### Disability

- International Classification of Functioning Disability and Health (ICF)
- Types, Causes and Prevention of Disability
- Concept of impairment and disability
- Stigmatization
- Discrimination
- Disability Act 2006, Act 715
- Identifying schemes for empowering people with disability
- Role of a nurse in prevention of Disability
- Physical impairment to communication

### Rehabilitation

- Types of rehabilitation
  - o Emphasis on Community Based Rehabilitation
- Members of rehabilitation and their roles (intersectoral collaboration in Rehabilitation)
- Role of a nurse in rehabilitation
- Rehabilitation levels; primary, secondary, tertiary
- Rehabilitation tools
- Role of traditional healers (*in relation with disability*)
- Under nutrition (*in relation with disability*)
- Community *inclusive* participation
- Burns (*and Buruli ulcer related to bandaging to prevent contractures*)
- Dislocation/Fractures/Amputation

### Child Health

- Normal growth and development (Developmental milestones from birth to 5years)
- Factors influencing growth and Development
- General examination of a baby
- Signs of developmental delay
- Guidelines for identifying childhood disability
- Management of the new born
- Health education and e. early detection and treatment
- Early stimulation and play
- Positioning and handling of high risk infants / cerebral palsy
- Common congenital abnormalities
- School services (Team members and their roles)
- Common Childhood disability Disorders
  - o Childhood Autism
  - o Attention deficit hyperactivity disorder
  - o Intellectual Developmental Disorder
  - o William Syndrome

- Talipes
  - Special home visits to; adults and children with disability
- Demonstration lecture
- Basic principles of Positioning and handling of children with disability
- Proposed Tutor for training

Registered Mental Nursing

RMN 321 community psychiatric nursing and community based rehabilitation ii

PHN 321 Public Health Nursing

Registered Midwifery

PHN 321 Public Health Nursing

RMD 223 Physiology And Management Of The High Risk Neonate

Registered Nurse Assistant(Clinical

NAC 041 Rehabilitation and Health Promotion

NAC 033 introductory child health

Registered General Nursing

RGN 321 Community based rehabilitation

RGN 123 Health promotion

Post NAC/NAP Midwifery

RMP 215 Physiology and Management of High Risk Neonate.

RMP 215 Public Health and Family Planning In Midwifery

Registered Nurse Assistant (Preventive)

RNAP programmes (Community health nursing)

**NAP 024** Intro Child Health

NAP 031 Community

Registered Community Nursing (RCN)

RCN123 P&P of Community Nursing and administration 1

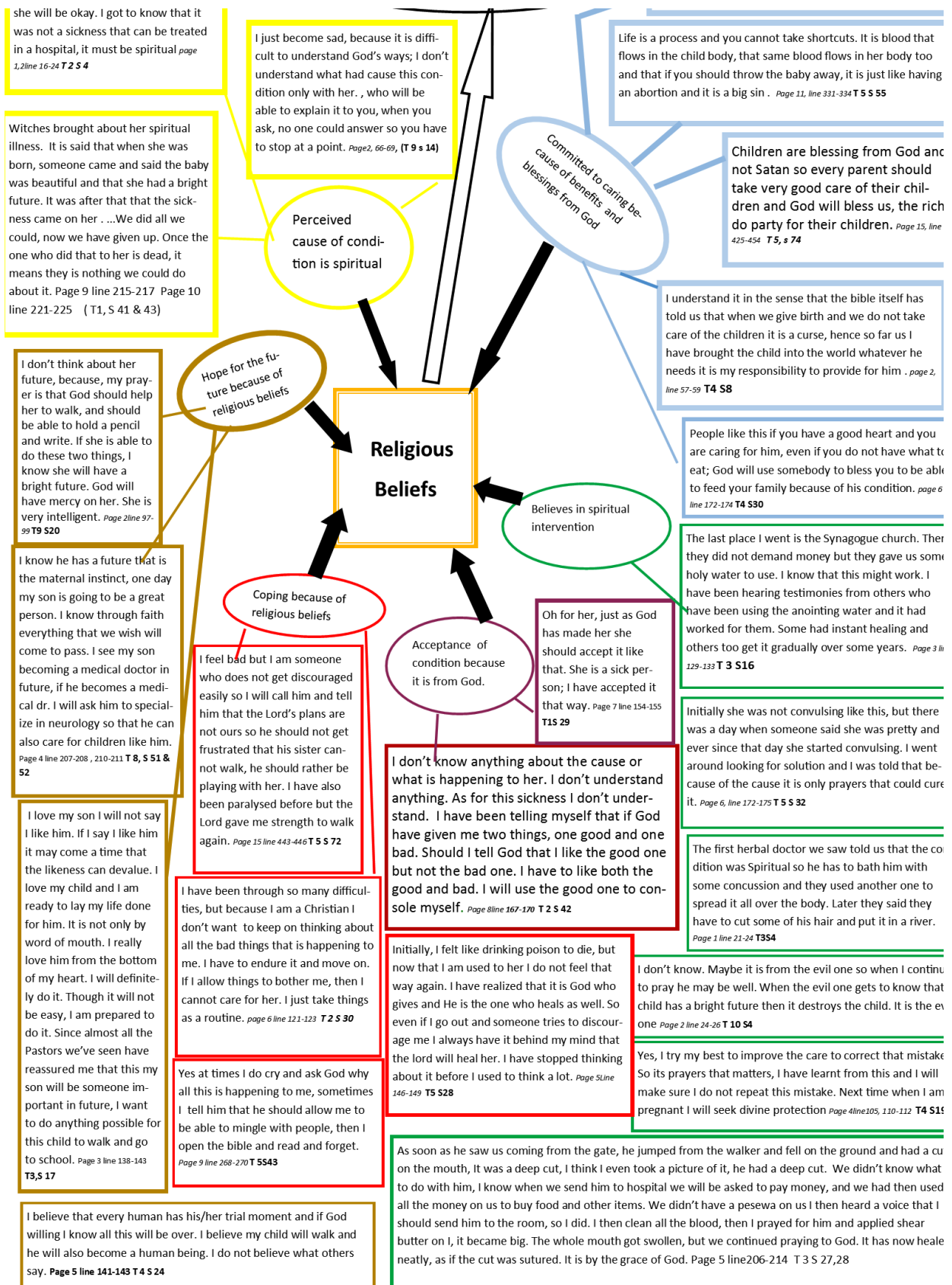
PNM 121 Human Growth and Development



## **Appendix VII Findings and Analysis**

- Extracts of significant statements and formulation of meanings from transcript 2
- Example of theme cluster mapping

	SIGNIFICANT STATEMENT	Formulated Meaning
1.	<p>To be honest with you I don't know what is happening to my daughter, all that I know is that when I gave birth to her she was not strong , she was floppy and for all her life she had never sit, walk or talk. I have tried every type of medicine but they all simply not working.</p> <p>She is now thirteen years old, I am still looking for a cure. Any medicine that anyone will introduce to me I will give it to her.</p> <p>Page 1 <b>Line 3-7</b></p>	<p>Mother describes the child according to the functional level</p> <p>Mother had tried using medication to treat CP</p> <p>Mother still looking for cure after thirteen years</p>
2.	<p>I had a very difficult labour, they were twins, after delivery she did not cry but the sister did, although she was fine, she was not like the sister. Three days after their delivery, her skin colour changed into yellow, and she couldn't suck the breast. We sent her to see a herbalist who gave us medicine</p> <p>1 <b>9-12</b></p>	<p>Mother's first option for solution was a herbalist.</p> <p>Mother monitor development of child by comparing her with the twin sister</p>
3.	<p>To bath her, she got a bit better and started sucking the breast. She could suck but it was not like her sister. She will suck just a little.</p> <p>I have been thinking that she is having some sickness but no one has been able to explain to me the type of sickness.</p> <p>1 <b>14-16</b></p>	<p>Mother's thought about the condition had not been answered</p>



## **Appendix VIII – Ethical Approval**

- **Ghana Health Service**
- **Coventry University**

**GHANA HEALTH SERVICE ETHICAL REVIEW COMMITTEE**

*In case of reply the  
number and date of this  
Letter should be quoted.*

*My Ref. : GHS-ERC: 3  
Your Ref. No.*



Research & Development Division  
Ghana Health Service  
P. O. Box MB 190  
Accra  
Tel: +233-302-681109  
Fax + 233-302-685424  
Email: nitadzy@yahoo.com

20th December, 2013

Gifty G. Nyante,  
School of Allied Health Sciences  
College of Health Sciences  
University of Ghana

**ETHICAL APPROVAL - ID NO: GHS-ERC: 06/11/13**

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol titled:

**"An exploration of the experienced and perceptions of primary caregivers with cerebral palsy living in rural communities in Ghana"**

This approval requires that you inform the Ethical Review Committee (ERC) when the study begins and provide Mid-term reports of the study to the Ethical Review Committee (ERC) for continuous review. The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Please note that any modification without ERC approval is rendered invalid.

You are also required to report all serious adverse events related to this study to the ERC within seven days verbally and fourteen days in writing.

You are requested to submit a final report on the study to assure the ERC that the project was implemented as per approved protocol. You are also to inform the ERC and your sponsor before any publication of the research findings.

Please always quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....  
DR. CYNTHIA BANNERMAN  
(GHS-ERC VICE-CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

**REGISTRY RESEARCH UNIT**  
**ETHICS REVIEW FEEDBACK FORM**

(Review feedback should be completed within 10 working days)

**Name of applicant:** Gifty Nyante.....

**Faculty/School/Department:** [Faculty of Health and Life Sciences] Physiotherapy and Dietetics

**Research project title:** AN EXPLORATION OF THE EXPERIENCES AND PERCEPTIONS OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY LIVING IN RURAL COMMUNITIES IN GHANA

Comments by the reviewer

**1. Evaluation of the ethics of the proposal:**

No issues with the proposal at all. This is a carefully considered proposal. All areas have been addressed appropriately and guidelines followed.

Assuming you are getting ethical approval from authorities in Ghana, as this is essentially across 2 sites, then this is approved. It indicates that the Health Service in Ghana is already involved. This is also referred to within the main proposal.

Also, it says that there are 3 researchers. It may be helpful to say who they are within the project details.

A very valuable piece of work which will highlight support or lack of support for children with CP.

**2. Evaluation of the participant information sheet and consent form:**

I did feel that the issues which are to be addressed with in the interview process will require very careful and sensitive handling especially with communication with the participants.

Please make sure childrens' names are anonymised as these can be identified from the interview guide.

On the interview guide, q 11 does not make sense. It needs to be rewritten.

**3. Recommendation:**

(Please indicate as appropriate and advise on any conditions. If there any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

- |  |   |
|--|---|
| <input checked="checked" type="checkbox"/> | Approved - no conditions attached   |
| <input type="checkbox"/>                   | Approved with minor conditions (no need to re-submit)   |
| <input type="checkbox"/>                   | Conditional upon the following – please use additional sheets if necessary (please re-submit application) |
| <input type="checkbox"/>                   | Rejected for the following reason(s) – please use other side if necessary                                 |
| <input type="checkbox"/>                   | Not required  |

**Name of reviewer:** Anonymous .....

**Date:** 03/10/2013 .....